

**Intersecting sexuality, gender, race & citizenship:  
Mental health issues faced by  
Immigrants & Refugees living with HIV/AIDS**

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## Executive Summary

### Purpose of the report:

This report consists of three key sections: a literature review on mental health issues affecting immigrants and refugees living with HIV (I&R-PHAs); the report on a program scan of existing mental health services for immigrants and refugees living with HIV in Toronto; the findings of a community focus consultation with service providers and I&R-PHAs; and to discuss the implications for research in this area.

### Summary of the Key Findings of the Literature Review and Program Scan:

- **The changing demographics of HIV/AIDS:** To some extent, the changing demographics of the HIV/AIDS affected populations mirror the changing demographics of Ontario and Canada. Over the last two decades, Canada's population has become increasingly diverse with over 18% (or 5.4 million) of its population being immigrants. Data from Census 2001 show that 3 million people or 26.8% of the Ontario population were foreign-born. Of the one million immigrants that arrived in Ontario between 1991 and 2001, 80% came from Asia (58.1%), Americas (14.6%) and Africa (6.8%). Moreover, while the Toronto Census Metropolitan Area has 41% of Ontario's population, it received 77% of its immigrants. These demographic changes have significant implications for the health service sector in terms of population health trends, changing health needs and its capacity to provide effective and efficient services, including HIV/AIDS services.
- **Changing contexts of HIV & AIDS:** Today, institutions and service providers in the HIV/AIDS health care sector are faced with the challenge of providing effective and efficient services due to the changing contexts of HIV and AIDS. The *HIV and AIDS in Canada: Surveillance Report to December 2003* shows significant changes in the proportion of positive HIV tests and AIDS cases attributed to the different exposure categories. The proportion of reported AIDS cases attributed to White Canadians has decreased from 86.8% before 1993 to 54.3% in 2003 while the proportion of AIDS has increased from 8.4% to 21.5% among Black Canadians and from 1.2% to 13.4% among Aboriginal peoples. Moreover, the heterosexual exposure category of positive HIV tests has increased from 7.5% before 1995 to 36.9% in 2003. Females now account for 25% of all positive HIV cases.
- **HIV/AIDS and mental health:** Recent advances in HIV treatments have led to increased longevity and the overall health improvement in many people living with HIV/AIDS (PHAs). The evolution of HIV/AIDS into a chronic health condition has presented new challenges

for PHAs. Since its emergence in the early 1980s, HIV/AIDS has been a disease with profound mental health impact due to its neuropsychiatric, psychosocial and economic effects associated with morbidity, mortality, stigmatization related to sexuality, poverty and substance use. Today, PHAs have to deal with additional demands such as the long-term adverse effects of HIV treatments; the psychosocial impact of living with a stigmatizing chronic illness; and coping with uncertainty and fluctuating health conditions. This literature review finds that reduced neurological functioning, depression, anxiety and other neuropsychiatric conditions are common among PHAs. At the same time, depression and other psychiatric conditions are shown to have adverse effects on HIV treatment adherence and to contribute to increased mortality, particularly among marginalized women. Thus, within this new context, mental health services have become increasingly important in the overall treatment and management of HIV/AIDS.

- **Lack of research on the mental health of immigrant and refugee PHAs:** While a substantial proportion of research literature has begun to address mental health issues among PHAs, literature pertaining to immigrant and refugee PHAs(I&R-PHAs)is scant. Existing literature reflects a number of significant knowledge gaps:1) most of the studies are done in the US and focus mainly on the identification of mental health or psychiatric problems among PHAs or the impact of mental health problems on treatment adherence, offering little information on effective strategies or models of best practices that contribute to the improvement of mental health among PHAs; 2) most of the studies still focus on gay White males; 3) research subpopulations are often defined by race or ethnicity categories, but rarely by the citizenship or migration status of the research participants; 4) existing Canadian studies on I&R-PHAs are limited and they tend to focus on HIV screening, risk factors or prevention variables; and 5) studies on PHAs of multiple marginalities -- immigrant/refugee PHAs who are intravenous drug users (IDUs), or sex workers, or men who have sex with men (MSM), or transgendered/transsexual -- are virtually non-existent. These knowledge gaps have significant implications for the development and provision of inclusive and accessible HIV/AIDS treatment and services for I&R-PHAs in Ontario and Canada.
- **Existing literature on the mental health of PHAs of color:** As few published studies on HIV/AIDS and mental health identify participants as immigrants or refugees, this literature review has to draw knowledge from studies of immigrants and refugees in general and

studies of PHAs of ethnoracial backgrounds. Findings show that immigrants and refugees experience a high level of settlement stress. Their health outcomes are influenced by determinants such as social support; pre-migration experiences; citizenship and social status; access to education, employment, adequate housing and health services; personal coping resources, community connections and social inclusion. Research has also demonstrated that discrimination and social inequities manifested are strongly associated with underemployment, unemployment, poverty and health disparity among recent immigrants and refugees. Among PHAs of color, there is strong evidence that discrimination, social exclusion and poverty contribute to the increase of HIV risks, poor management of HIV and AIDS and higher rates of depression and other psychiatric problems; these findings are particularly pertinent among urban racialized HIV positive women, who are also caregivers to their children and other family members.

- **Local knowledge and a program scan:** A 2001 study conducted by CAAT and funded by OHTN identified the mental health needs of I&R-PHAs as a priority issue in HIV/AIDS care. Within the current project, a program scan of 10 settlement and mental health services in the Greater Toronto Area (GTA) was conducted to assess the level of ease for I&R-PHAs, who have difficulty using English or French, to access mental health services. In one situation, the project consultant was referred to 8 different agencies before she was finally referred to an ethnospecific ASO for mental health care. Findings indicate the need for improved coordination of services and an increased awareness of HIV/AIDS and related health issues among non-AIDS service organizations serving immigrants and refugees.

### **Key Findings of the Focus Group Consultation**

Two focus groups, one with I&R-PHAs and one with service providers, were conducted in order to identify the research priority on mental health issues of I&R-PHAs. Key findings include:

- **Defining mental health:** Participants emphasized that mental health is connected to one's emotional, physical and social health. They identify decreased brain functioning, physical illnesses, disabilities, discrimination, social isolation and economic inequities as key stressors in their life.
- **Stress:** The immigration process was identified as the major source of stress among refugee and non-status PHAs. Other stressors are related to social determinants including poverty, under-housing, unemployment, access to food, financial and social security.

- **Depression:** Depression and other mental health problems are reported to be related to physical illnesses, fear of dying in isolation, fear of stigmatization with disclosure of HIV status, and decreased level of function. For PHA mothers, the fear of having nobody around to take care of their children if they became ill contributes to their depression.
- **Quality of life and existential crises:** A number of PHAs raised the issues of quality of life in the focus group. Their perception of decreased quality of life is related to their struggle for survival, their experience of social exclusion and declining health. Many experience anxiety, depression and a sense of deep loss as they are faced with tremendous uncertainty about their health and their future in Canada.

**Research priority:** Focus group participants identified a number of research priorities:

1. Assessment of current mental health services for immigrant/refugee PHAs:
  - What types of services exist for immigrant/refugee PHAs? What types of services are PHAs accessing now?
  - What types of services have been found to be effective for immigrant/refugee PHAs who are accessing service? Why are they effective?
  - What needs to be in place for services to become more accessible for immigrant/refugee PHAs who are not accessing these services?
  - How to facilitate a better coordination of these services?
  - Services and care providers: What do they know about the intersection of HIV/AIDS and mental health and migration? How much do they know about HIV/AIDS in relation to mental health and immigration?
2. What is the impact of mandatory testing on the mental health of immigrant/refugee PHAs?
3. How does “time” play in the lives of I&R-PHAs as both immigration and living with HIV/AIDS involve long-term processes? What is the relationship between time and mental health among I&R-PHAs who are newcomers and those who have been in Canada for a period of time.

## **Conclusion**

Findings from the literature search and the focus group consultation suggest that in addition to the stressors faced by PHAs in general, immigrant and refugee PHAs experience additional stressors related to the immigration and settlement processes, racism, social exclusion, poverty, under-housing, isolation, and barriers to accessing services. Findings from the program scan

suggest that it is difficult for I&R-PHAs with language and cultural barriers to access mental health services. While participants identified a number of determinants of mental health for I&R-PHAs, there was a general consensus that a lack of comprehensive knowledge exists on the mental health beliefs and mental health needs of I&R-PHAs; the intersecting effects of HIV/AIDS and migration on mental health; types of mental health services required; how to increase the effectiveness of existing services for the mental health needs of I&R-PHAs; and how to improved access to mental health services for I&R-PHAs.

## **Recommendations**

Based on the findings of this report on the mental health issues and needs of immigrants and refugees living with HIV/AIDS, the following recommendations have been identified:

1. As the health of I&R-PHAs is affected by multiple social and economic determinants, comprehensive analysis on current public policy pertaining to immigration, employment, health care and systemic discrimination is recommended.
2. As effective HIV/AIDS policy and strategies need to be developed based on “inclusive” evidence, the lack of knowledge and research on the mental health needs of immigrant, refugee and non-status PHAs continues to perpetuate knowledge and service gaps and health disparity among I&R-PHAs. It is recommended that research on the mental health needs of I&R-PHAs be set as a priority.
3. As community empowerment requires the opportunity for individuals and communities to work together to identify their health issues and take control of their health, the use of a community action paradigm to conduct inclusive research on mental health and other health issues affecting I&R-PHAs is recommended.
4. To improve service effectiveness and efficiency for I&R-PHAs, evaluation research on current service coordination among HIV/AIDS care, mental health, legal and immigrant/settlement services is recommended.
5. To increase service effectiveness and efficiency for I&R-PHAs, a process that facilitates dialogue between I&R-PHAs and stakeholders in HIV/AIDS care, mental health, legal and immigrant/settlement services is recommended.
6. To increased service effectiveness and efficiency for I&R-PHAs, staff training on the intersecting effects of citizenship, sexuality, gender, race, class and any other

marginalization is recommended for service providers in the HIV/AIDS care, mental health, legal and immigrant/settlement sectors.

## **Introduction**

The purpose of this report is to present findings of a literature review on mental health issues affecting immigrants and refugees living with HIV (I&R-PHAs); report on a program scan of existing mental health services for I&R-PHAs in Toronto; present findings of community focus consultation with service providers and I&R-PHAs; and to discuss the implications for research in this area. The report is organized into three parts: the literature review, the program scan and the community focus group consultation.

### **Part I: The literature review**

The literature review consists of three subsections: A) Global HIV/AIDS Epidemic; B) HIV and AIDS surveillance data up to December 2003; C) general mental health issues and needs of people living with HIV/AIDS (PHAs); and D) mental health issues of I&R-PHAs. *Subsection A* provides a brief overview of HIV/AIDS prevalence around the world. *Subsection B* provides an overview of the current number of cases of HIV and AIDS in Canada and the changing trends among groups of Canadians who are now living with HIV and AIDS. As there is a scarcity of Canadian literature on I&R-PHAs, *Subsection C* draws upon research that has been done in the general PHA population and in other countries. *Subsection D* reviews the limited literature on the mental health of I&R-PHAs.

### **Part II: The Program Scan**

Since the published literature on mental health issues and the needs of immigrant and refugee PHAs in Canada is scant and there is a gap in understanding the accessibility and utilization of mental health services by this population, a program scan was performed to acquire a glimpse into the current mental health services for immigrant and refugee PHAs in the Greater Toronto Area. Due to time and resource constraints, only a 'scan' was performed. The findings, by no means, represent a comprehensive analysis; however, it does identify the need for evaluation research in this area. Key findings of the program scan suggest the following preliminary program and service needs for immigrant and refugee PHAs:

- Improved coordination of services
- Improved quality of services with HIV/AIDS awareness training

- Improved quality of services with Anti-AIDSphobia training
- Language services and interpretation
- Sensitivity and compassion
- Flexibility around service catchments
- More mental health services and programs for immigrant PHAs
- Consideration and service provision for undocumented PHAs.

### **Part III: The Community Focus Consultation**

Based on the principles of empowerment<sup>1</sup> and community capacity building<sup>2</sup>, two community consultation focus groups (one with immigrant and refugee PHAs, one with service providers) were conducted to identify the research priorities related to the mental health issues and needs of immigrants and refugees living in Canada. In addition, the knowledge generated from the focus group augmented the findings in the literature review. Key research priority and questions generated by participants of the focus groups include:

- How do the current social welfare and health care systems affect the mental health of immigrant/refugee PHAs?
- When immigrant/refugee PHAs have to go through immigration legal processes and deal with HIV status/illness simultaneously over a long period of time, what are the effects on their emotional and mental health?
- What are the effects of under-housing on the physical and mental health of immigrant and refugee PHAs?
- What is the impact of mandatory testing on the mental health of immigrant/refugee PHAs?
- Research on current mental health services for immigrant/refugee PHAs:
  - What types of services exist for immigrant/refugee PHAs? What types of services are PHAs accessing now?
  - What types of services have been effective for immigrant/refugee PHAs who are accessing service? Why are they effective?
  - What needs to be in place for services to become more accessible for immigrant/refugee PHAs who are not accessing service?

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<sup>1</sup> Empowerment is “a social-action process that promotes participation of people, organizations and communities towards the goal of increased individual and community control, political efficacy, improved quality of community life, and social justice” (Wallerstein, 1992). When applied to research, it means a commitment among researchers and service providers to collaborate in developing a methodology that truly reflects the needs of the participants and providing opportunities for meaningful and equitable participation, including the identification of research priorities and input into research methods.

<sup>2</sup> Community capacity is “the interaction of human capital, organizational resources, and social capital existing within a given community that can be leveraged to solve collective problems and improve or maintain the well-being of a given community... through informal social processes and/or organized effort” (Chaskin, 2001).

- How to facilitate a better coordination of these services?
- Research on services and care providers:
  - What do we know about the intersection of HIV/AIDS and mental health and migration?
  - How much do care-providers know about HIV/AIDS in relation to mental health and immigration [i.e. their level of knowledge]?

## Part I: Literature Review

### A) The Global HIV & AIDS Epidemic (UNAIDS, 2004)

Worldwide the number of people living with HIV grew from 35 million in 2001 to 38 million in 2003. In the same year, almost three million died from AIDS; over 20 million have died since the first cases of AIDS were identified in 1981. With increased global travel and movement of people related to migration, Canada can no longer view HIV/AIDS as a local issue. Global HIV trends have indirect effects on the HIV epidemiology in Canada. The following summarizes global trends by regions:

**Asia:** The HIV epidemic in Asia is growing rapidly, as shown by the sharp increase in HIV infections in China, Indonesia and Vietnam. An estimated 7.4 million people are living with HIV in the region, of which 1.1 million became newly infected last year. In Asia, the HIV exposure categories continue to largely to be IDU, MSM, sex workers, clients of sex workers and their immediate sexual partners.

**Africa:** It is estimated that 25 million people are living with HIV in Sub-Saharan Africa. The stabilized HIV prevalence rates are mainly due to a rise in AIDS deaths and a continuous increase in new infections. It is important to note that HIV prevalence varies significantly across the African continent: Southern Africa (above 17%; with Botswana and Swaziland above 35%); West Africa (10% and below) and Central/East Africa (4% to 13%).

The prevalence rates in North Africa and the Middle East appear low at about 480,000; however, systematic surveillance of the epidemic is underdeveloped and HIV may be spreading undetected, particularly among high-risk groups such as IDUs and possibly among MSM as male-male sex is widely condemned and illegal in many places.

**Eastern Europe and Central Asia:** The HIV prevalence rate has increased from 160,000 in 1995 to about 1.3 million in 2003. More than 80% of PHAs are under age 30. Estonia, Latvia, the Russian Federation and Ukraine are the worst-affected countries, but HIV also continues to spread in Belarus, Kazakhstan and Moldova. The main exposure categories are IDUs and their sex partners. Russia has over 3 million IDUs and has a high HIV prevalence rate. The HIV Infection rate among women has increased from 25% in 2001 to 33% in 2003.

**Latin America:** About 1.6 million people are living with HIV in Latin America. The low national prevalence does not reflect the high concentration rates found in certain cities. For example, while Brazil has a national prevalence rate below 1%, some of its cities have prevalence rates of 60%. The exposure categories are mostly IDUs and MSM. However, in Central America, HIV is spread predominantly through sex among heterosexuals and MSMs.

**Caribbean:** About 430,000 people in the Caribbean countries are living with HIV. The national prevalence rates are as follows: Bahamas (3%), Trinidad & Tobago (3%) and Haiti (5.6%, highest outside of Africa). The exposure categories are mostly heterosexuals and in some places sex workers.

**High-income countries:** An estimated 1.6 million people are living with HIV in these countries. Access to antiretroviral therapy enables PHAs to stay healthy and survive longer than PHAs elsewhere. Data shows that HIV infections are on the rise in the US and Western Europe. Half of all new infections in recent years have been among African Americans, indicating the effects of social inequities and marginalization on the spread of HIV within high-income countries.

## **B) HIV & AIDS in Canada**

### **1) HIV surveillance data in Canada**

Since HIV testing started in 1985, a total of 55,180 positive tests have been reported to the Centre for Infectious Disease Prevention in Canada. The annual number of positive tests has declined from 2,996 in 1995 to 2,187 in 2001. However, it has increased to 2,504 in 2002 and 2,482 in 2003 (Figure 1). This increase may be attributed to the addition of HIV screening to routine immigration medical assessment started in January 2002<sup>3</sup>, and the increased admission of certain groups of immigrant who would have previously been considered medically inadmissible (Health Canada, 2004).

Data up to the end of 2003 also reflect significant changes in the proportion of HIV positive tests attributed to the different exposure categories (ibid.):

- **MSM:** While the proportion of HIV positive tests attributable to the exposure category of men having sex with men (MSM) remains high, it has decreased from 75% between 1985-1994 to 37% till the mid to late 1990s, with a slight increase to 44% in the last 3 years (ibid., figure 2).
- **IDU:** The proportion of HIV positive tests attributed to injection drug use has decreased from 28.7% in 1998 to 17.5 % in the first half of 2003.
- **Females:** Females now represent a growing proportion of positive HIV cases. Between 1985 and 1992, females accounted for 8.9% of all HIV positive cases; overall they accounted for approximately 25% of all cases. The increase is most notable in the 15-29 and 30-39 age groups (figure 3).
- **Heterosexual:** The diverse heterosexual exposure category, including “heterosexual contact with a person who is either HIV-infected or at increased risk of HIV, heterosexual as the only identified risk, or origin in a country where HIV is endemic”, has increased steadily from 7.5% before 1995 to 36.9% in 2003. From 1998 to 2003, HIV positive test

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<sup>3</sup> Applicants for a permanent resident visa and their dependants; foreign nationals from designated countries or territories applying to stay in Canada for a period of greater than six months; applicants intending to work in an occupation in which the protection of public health is essential; and anyone claiming refugee protection in Canada, are required to go through HIV testing (CIC, 2002). For details, refer to Citizenship and Immigration Canada. *Immigrant and Refugee Protection Act. Statutes of Canada 2001*. Chapter 27. URL: [http://www.cic.gc.ca/english/pdf/pub/C-11\\_4.pdf](http://www.cic.gc.ca/english/pdf/pub/C-11_4.pdf)

attributed to heterosexual exposure from an endemic country has increased from 2.9% to 10.2%.

- **Persons from HIV endemic countries:** Up until December 2002, a total of 2,630 persons living with AIDS in Ontario were from HIV endemic regions; approximately half of them are from Africa and half from the Caribbean. While the overall prevalence rates among immigrants from the endemic regions appear to be low in numbers, they are 20-fold higher than among other heterosexual non-injection persons in Ontario. There is evidence that considerable transmission may have occurred after arriving in Canada. It is also estimated that there are over 400 MSM from HIV-endemic regions, with several thousand men at risk for infection (Remis & Merid, 2003).

## **2) AIDS surveillance in Canada**

Up until December 2003, there were 19,344 cumulative cases of AIDS reported in Canada. The annual number of reported AIDS cases increased throughout the 1980s and early 1990s and peaked in 1993 with 1,953 cases. After 1993, as in other industrialized countries where effective antiviral therapy is available, the number of reported cases of AIDS has declined and leveled off to between 500 and 600 diagnoses per year (Health Canada, 2004).

The three highest proportions of reported AIDS cases by age are: 30 to 44 years (60.4%); 45 to 59 years (19.4%); and 15 to 29 years (15.9%). Over the last 10 years, adult females have accounted for a larger proportion of diagnosed AIDS cases, rising from 7.0% in 1993 to 24.2% in 2003. Females now represent 42% of AIDS diagnoses among those aged 15 to 29 years, 25.4% among those aged 30 to 44 years and 18.2% among 45- to 59-year-olds (ibid). During the same period, the proportion of AIDS cases among MSM has fallen from 73.8% in 1993 to 35.3% in 2003, while the diverse heterosexual exposure category has increased from 13% in 1993 to 43.8% in 2003. Reported adult cases of AIDS among IDU have risen steadily since 1979 to a peak of 21.5% in 1998; there was a decrease to 14.8% in 2001 but an increase to 19.1 % in 2002.

## **3) HIV, AIDS and ethnicity**

While information on HIV or AIDS among immigrants or refugees in Canada is not normally collected, information on ethnicity and HIV/AIDS has been collected routinely since 1982 (Hyman, 2001). "The proportion of reported AIDS cases attributed to White Canadians has been decreasing over time, from 86.8% before 1993 to 54.3% in 2003. This decrease is coupled with

increases seen among both Black and Aboriginal Canadians. Black Canadians represented 8.4% of cases before 1993 and 21.5% in 2003. During the same period the number of cases among Aboriginal Canadians increased from 1.2% to 13.4% (Health Canada, 2004; Figure 4).

Remis & Whittingham (1999 as cited in Hyman, 2001) suggest that in Ontario, HIV/AIDS is becoming prevalent among immigrants and refugees born in endemic countries; from 1981 to 1995, they accounted for 2.9% of HIV positive tests and in 1997 and 1998, they accounted for 14% of the cases. It is estimated that 46% of HIV infections among immigrants from the Caribbean and 30% of infection among immigrants from Sub-Saharan Africa were acquired in Canada.

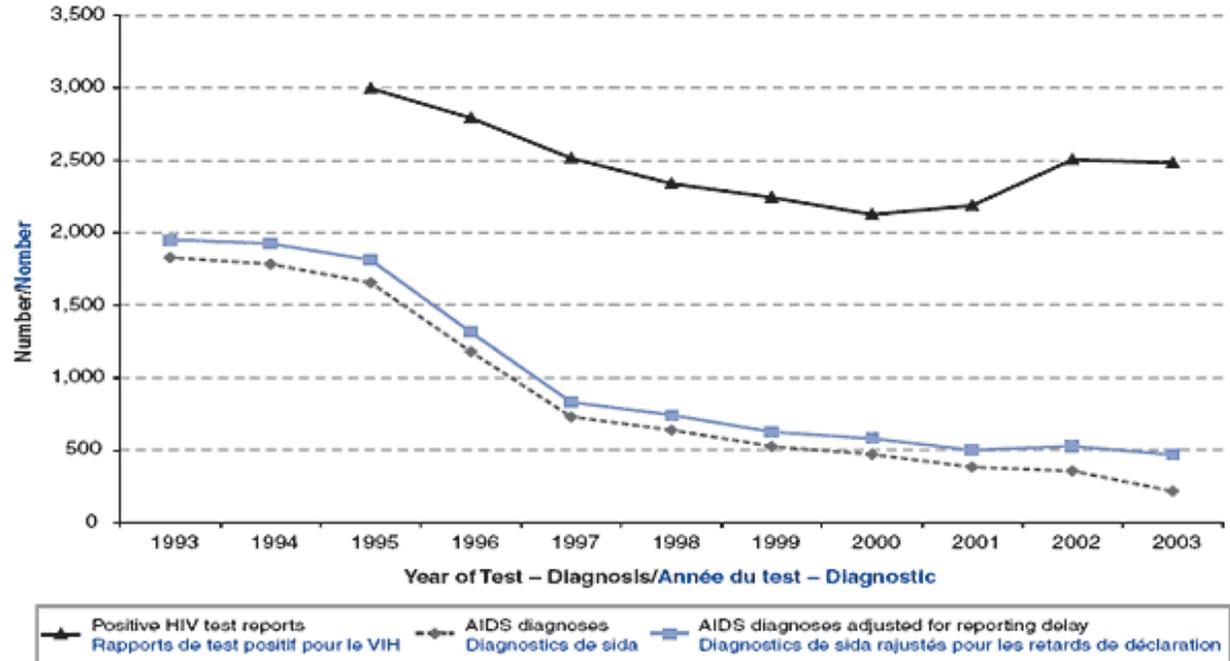
However, existing HIV and AIDS data present a dilemma. Health Canada (2004) cautions that the current HIV & AIDS reported ethnicity data must be interpreted with caution due to a number of limitations associated with reporting (Table 1 and 2):

- Reporting of ethnic status is not complete: Since 1979, approximately 88% of reported AIDS cases have included information on ethnicity. However, for positive HIV test reports, ethnicity data have only been collected since 1998, of which only 30% have included information on ethnicity.
- Limited choice for identification of ethnic status: Current choice of ethnicity classification is dependent on how health care providers consult the patients; constrained by a defined list of ethnic groups for reporting; and the willingness for patients to identify their ethnic backgrounds.
- Variation in the completeness of reporting ethnic status: Currently, Ontario and Quebec do not report ethnic status with positive HIV test report; thus, ethnic status identified in Canada's surveillance reports must not be viewed as representative of all of Canada. In addition, ethnic populations are not spread evenly across Canada, resulting in differential representation of specific communities.

Thus, the current HIV and AIDS surveillance system is far from perfect. With the changing demographics of Canada's populations related to migration and global travel, HIV and AIDS surveillance data that reflect the population diversity are needed to guide programs, services, research and policy development.

The figures and tables on the following pages are taken from Health Canada (2004). *HIV and AIDS in Canada: Surveillance Report to December 31, 2003*. Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Population and Public Health Branch, Health Canada.

**Figure 1 Positive HIV test reports and AIDS diagnoses by year of diagnosis, 1993-2003**



**Figure 2 Positive HIV test reports by exposure category and year of test**

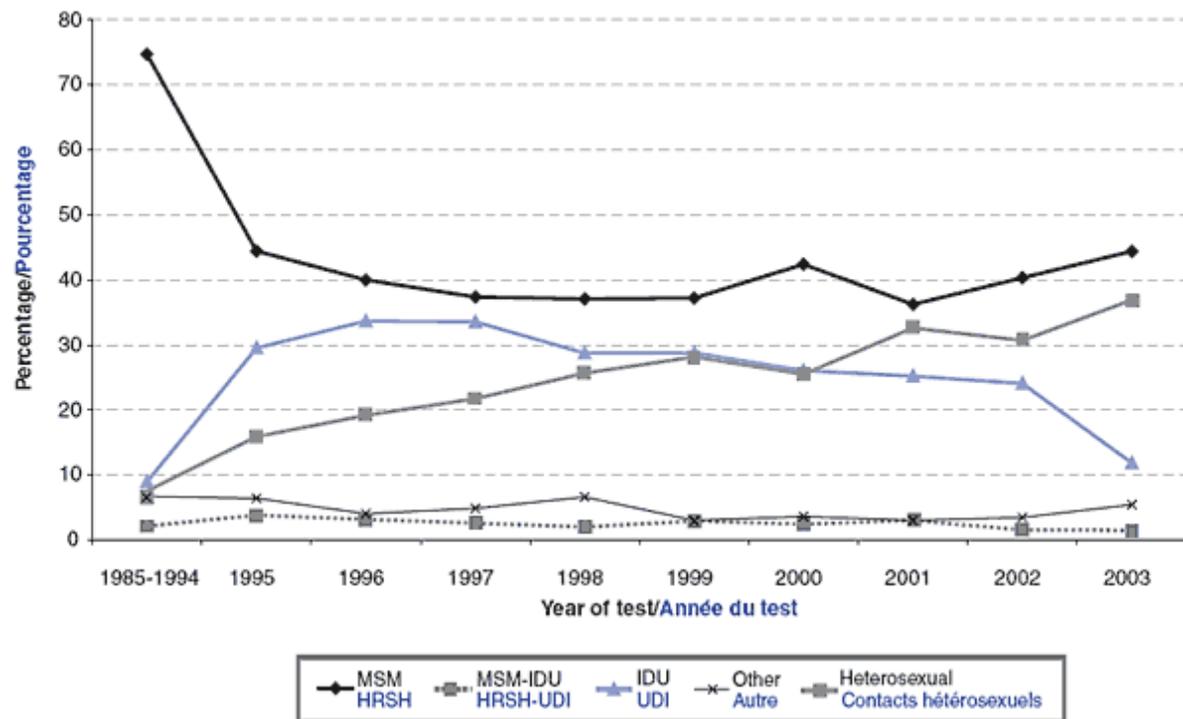


Figure 3. Proportion of females among positive HIV test reports by age group

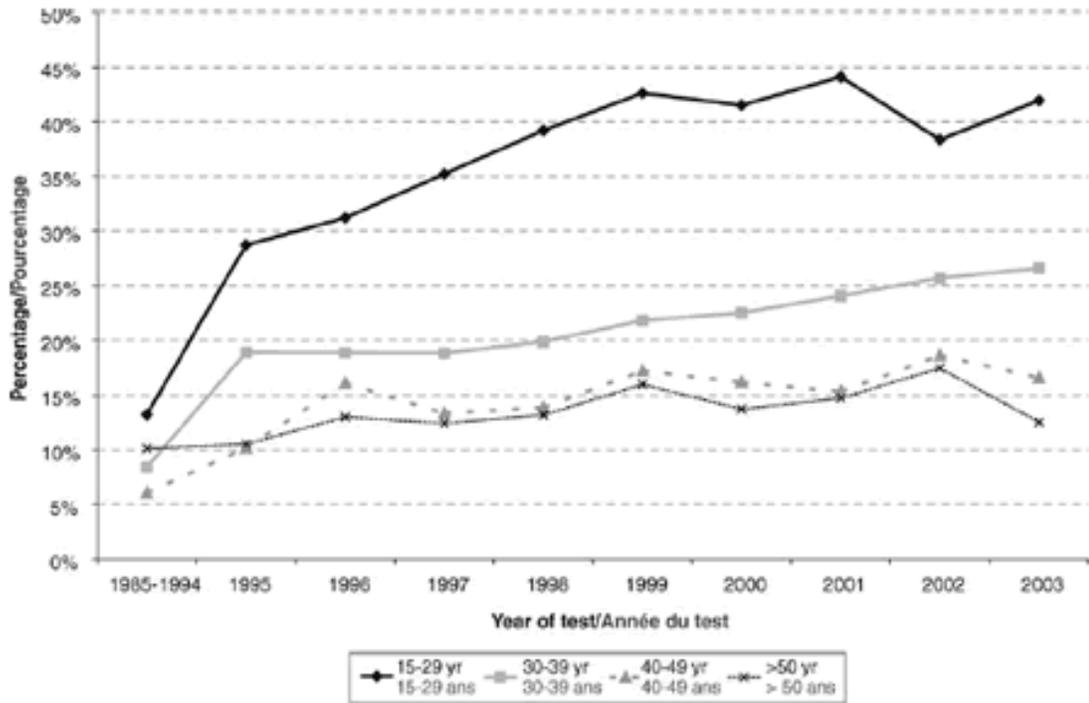
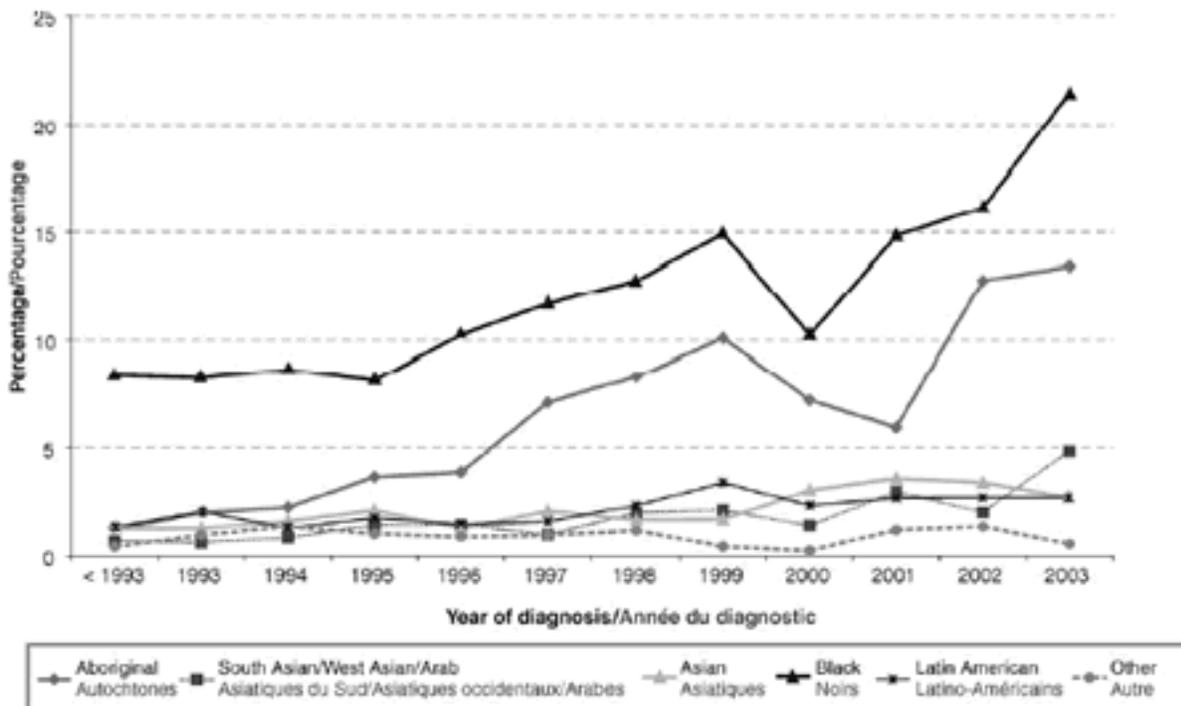


Figure 4. Non-White ethnic categories as a percentage of all reported AIDS diagnoses, by year of diagnosis (all ages)



**Table 1. Number of positive HIV test reports by year of test and ethnic status for those provinces that submitted ethnicity data between 1998 and December 31, 2003 (all ages)<sup>1,2</sup>**

Year of test	1998		1999		2000		2001		2002		2003 <sup>3</sup>		Total	
Ethnic Status	n	% <sup>2</sup>	n	%	n	%	n	%	n	%	n	%	n	% <sup>4</sup>
<b>Aboriginal<sup>5</sup></b>	121	18.8	168	24.3	155	22.2	188	26.2	176	24.3	74	25.3	882	23.4
<b>South Asian/West Asian/Arab<sup>6</sup></b>	20	3.1	12	1.7	8	1.1	2	0.3	9	1.2	3	1.0	54	1.4
<b>Asian<sup>7</sup></b>	14	2.2	20	2.9	34	4.9	17	2.4	30	4.1	8	2.7	123	3.3
<b>Black<sup>8</sup></b>	34	5.3	50	7.2	49	7.0	65	9.1	81	11.2	49	16.8	328	8.7
<b>Latin American<sup>9</sup></b>	14	2.2	14	2.0	22	3.1	11	1.5	24	3.3	3	1.0	88	2.3
<b>White</b>	434	67.6	420	60.7	429	61.4	430	60.0	399	55.2	135	46.2	2,247	59.7
<b>Other</b>	5	0.8	8	1.2	2	0.3	4	0.6	4	0.6	20	6.8	43	1.1
<b>Not reported</b>	1,697		1,552		1,428		1,470		1,781		2,190		10,118	
<b>Total</b>	2,339	100.0	2,244	100.0	2,127	100.0	2,187	100.0	2,504	100.0	2,482	100.0	13,883	100.0

1 It is important to note the limitations associated with this table, outlined in Appendix 2 of the original document on Data Limitations.

2 Provinces that submitted data include BC, AB, SK, MB, NB, NS, PE, NL, YT, NT, NU. Ethnicity data became part of provincial submission in 1998 for HIV.

3 Due to recent changes in reporting of HIV in British Columbia, ethnic status was unavailable for 2003. At this time all positive HIV test reports for 2003 are presented as 'not reported'.

4 Percentages based on total number minus reports for which ethnic status was not reported.

5 Includes Inuit, Metis, First Nations and Aboriginal unspecified.

6 For example, Pakistani, Sri Lankan, Bangladeshi as well as Armenian, Egyptian, Iranian, Lebanese, Moroccan.

8 For example, Somali, Haitian, Jamaican.

9 For example, Mexican, Central/South American.

7 For example, Chinese, Japanese, Vietnamese, Cambodian, Indonesian, Laotian, Korean, Filipino.

**Table 2. Number of reported AIDS cases by year of diagnosis and ethnic status (all ages)**

<b>Year of diagnosis</b>	1979-1997		1998		1999		2000		2001		2002		2003		Total	
<b>Ethnic status</b>	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	% <sup>1</sup>
<b>Aboriginal<sup>2</sup></b>	308	2.1	50	8.3	48	10.1	31	7.2	20	5.9	38	12.8	25	13.4	520	3.1
<b>S. Asian/ W. Asian/ Arab<sup>3</sup></b>	120	0.8	12	2.0	10	2.1	6	1.4	10	3.0	6	2.0	9	4.8	173	1.0
<b>Asian<sup>4</sup></b>	206	1.4	10	1.7	8	1.7	13	3.0	12	3.6	10	3.4	5	2.7	264	1.6
<b>Black<sup>5</sup></b>	1,267	8.6	77	12.8	71	14.9	44	10.2	50	14.8	48	16.2	40	21.5	1,597	9.4
<b>Latin American<sup>6</sup></b>	215	1.5	14	2.3	16	3.4	10	2.3	9	2.7	8	2.7	5	2.7	277	1.6
<b>White</b>	12,441	84.9	432	71.8	321	67.4	325	75.6	232	68.8	183	61.6	101	54.3	14,035	82.6
<b>Other</b>	101	0.7	7	1.2	2	0.4	1	0.2	4	1.2	4	1.3	1	0.5	120	0.7
<b>Not reported</b>	2,090		37		51		41		47		60		32		2,358	
<b>Total<sup>7</sup></b>	16,748	100.0	639	100.0	527	100.0	471	100.0	384	100.0	357	100.0	218	100.0	19,344	100.0

1 Percentages based on total number minus reports for which ethnic status was not reported.

2 Includes Inuit, Metis, First Nations and Aboriginal unspecified.

3 For example, Pakistani, Sri Lankan, Bangladeshi as well as Armenian, Egyptian, Iranian, Lebanese, Moroccan.

4 For example, Chinese, Japanese, Vietnamese, Cambodian, Indonesian, Laotian, Korean, Filipino.

5 For example, Somali, Haitian, Jamaican.

6 For example, Mexican, Central/South American.

7 Due to ongoing review of data in Alberta, there has been a redistribution of AIDS cases between exposure categories prior to 2001.

## **B) General Mental Health Issues & Needs of PHAs**

### **1) Stigma and stressors associated with HIV/AIDS**

With advances in medicine and technology, people are now living longer with HIV/AIDS; in other words living longer with a chronic disease and emotional distress which fluctuates with time. However, the HIV epidemic has a greater negative impact on the psychological and social functioning of individuals than other life threatening illnesses, due to the greater negative stigma and discrimination associated with HIV infection, and the greater likelihood for the partners and peers of PHAs to be either HIV positive or becoming so.

A newly diagnosed individual has to face a variety of challenges such as evaluating ones own sexual interactions with others in terms of transmission risk, learning the complexities of infection management and treatment, negotiating new relationships with health care providers, coping with the reactions, demands and responsibilities related to family and friends and facing restrictions from the external support system. Getting a HIV/AIDS diagnosis opens the way to significant life changes, and can easily strain the coping and spiritual resources of the individual and of the support network. These new challenges and demands have significant impact on the health of PHAs; a recent study (Ickovics, Thayaparan & Ethier, 2000, cited in Roberts & Miller, 2004) found HIV-infected women who were depressed having a shorter lifespan, than non-depressed HIV-infected women.

Compared to other illnesses, HIV is associated with a higher risk of external and internalized stigmatization; there is also significant concerns regarding secondary stigmatization of people who love and care for PHAs (Roberts & Miller, 2004), leading to changes in relationships and social dynamics between those who depersonalize, stigmatize, scapegoat or discriminate, and the people who are subjected to them (Gilmore & Somerville, 1994). Stigmatization inflicts intense emotional pain on those affected; in addition, people who are labeled may behave according to the labels as a way of coping and this may result in further discrimination, resulting in intense social isolation and feelings of abandonment among PHAs.

#### **1. a Older adults living with HIV/AIDS**

Older adults with HIV confront many demoralizing predicaments common to other HIV-infected age populations, such as discrimination, physical and cognitive decline and changes in social and sexual relationships. But they also have to face age-specific stressors such as coexisting health conditions (physical and mental), side effects and physical conditions resulting from HIV medication, and fewer coping resources. Increased psychological co-morbidity is common in

this age group, as even modest and anticipated changes associated with normal aging can tax the coping and adjustment efforts for them. More somatic symptoms have also been reported in this age group. Somatization has been related to lesser compliance with HIV-treatment regimens and led to the seeking of unnecessary medical care.

Elderly in general, report more depressive symptoms and higher levels of life-stressor burdens than younger people. Maintaining strict adherence to complex and inflexible HIV treatment regimens and facing other risks such as losing employment/housing/insurance etc. can easily tax the mental resources of older adults. Losing friends and family to AIDS or other diseases is one of the biggest stressors among older Americans with HIV/AIDS. They tend not to disclose their HIV status as readily as their younger counterparts. Drug interaction problems also persist, as they take HIV medication and medication for other conditions such as diabetes or arthritis (National Institutes of Health, 2004). Older adults also report a higher degree of somatization and interpersonal sensitivity and hostility, engaging in frequent temper outbursts and arguments. However, there is more evidence of similarities rather than differences between younger and older HIV-infected adults' mental health functioning (Heckman et al., 2002).

### **1. b Women living with HIV/AIDS**

Studies in developed countries have suggested a strong association between social inequalities and HIV infection among women (Strathdee et al., 2001; Kral et al., 2001; Spittal et al., 2002). Zierler and Kreiger (1997) have found that women PHAs in the US have been disproportionately poor, living in neighbourhoods burdened by poverty, drugs and violence. In addition, many women PHAs have to assume extra responsibilities related to gender differentials in society; for example, women PHAs carry the burden of pre-natal HIV testing and prophylaxis to prevent vertical transmission of HIV to their unborn children (Dodds et al., 2000); many women also neglect their own health as they continue their role as caregivers to their infected spouses and children (Ciambrone, 2003). Women PHAs with children are faced with worries and the need of planning for the care of their children as their health deteriorates and the likelihood of their death increases. Most children will need temporary or permanent non-parent alternative care by the time they reach school (European Collaborative Study, 1998).

Social support has been identified as a key factor that influences the health of women PHAs. In studying the adjustment factors of women diagnosed and living with HIV/AIDS, Bova (2001) finds that appraisal of an event may be more powerful than coping behaviors in explaining a person's adjustment to chronic illness. At the same time, the appraisal is influenced by

supportive others; it is not limited to an individualistic worldview but is created within the cultural milieu of the HIV positive individual.

### **1. c Children affected by and infected with HIV/AIDS**

According to a US survey completed in 1990, approximately 85% of women with AIDS were of reproductive age at the time of diagnosis, and the majority of the women already had children (Ellerbrock, Bush, Chamberland & Oxtoby, 1991). Although 90% of the children born to HIV-infected mothers are not infected themselves, the psychological impact of living in a HIV-infected family could be significant for these children. As previously mentioned, HIV infection is strongly associated with social inequities. Many families with HIV positive parents experience difficulties related to increased poverty, unstable housing, unemployment and substance abuse. The cumulative effects of these factors tend to put the children in the family at risk of mental health problems. In addition, the stigma associated with HIV/AIDS and the resulting secrecy is an additional burden for the children (Forsyth, Damour, Nagler & Adnopoz, 1996).

The behavior pattern of uninfected children who have infected parents is more of an internalized form, expressed as depression, withdrawal and attention deficits which can easily go unnoticed. Children of symptomatic mothers also show greater anxiety compared to children of asymptomatic mothers (Forsyth, Damour, Nagler & Adnopoz, 1996). In families where multiple members are infected, the experience of losing one or both parents, a sibling or close relative before one reaches adolescence could lead to significant mental health problems (Thorne, Newell & Peckham, 2000).

Approximately 40% of HIV positive children develop AIDS within the first four years of life. Abnormal neurological and associated conditions take the form of developmental delay, neurological symptoms, cognitive difficulties and sometimes behavioral problems. With a growing number of children surviving longer, visual-spatial and language problems are common. Recent studies show that parental intravenous drug use is a more important factor than HIV itself, in the emergence of behavioral difficulties in HIV positive children. Chronic illness in the parent or child, stigmatization and missed schooling may also contribute to the psychological and emotional difficulties observed in this age group (Campbell, 1997). Gaughan et al. (2004) find that children living with HIV/AIDS are at increased risk of psychiatric hospitalizations during childhood and early adolescence related to their knowledge of their HIV seropositive status and significant life events related to the diagnosis (Gaughan et al., 2004).

Another critical issue related to children living or affected by HIV/AIDS is disclosure, which poses an ethical dilemma when parents resist disclosure. For some children, the disclosure of their own HIV seropositive status or that of a family member may be delayed for a long period of time because of its associated discrimination and stigma (Wiener, Battles, Heilman, Sigelman & Pizzo, 1996). Disclosure of the children's HIV status often comes about because they are required to comply with a difficult drug or treatment regimen. The increasing use of combination therapy in the management of pediatric infection has resulted in many HIV-infected children surviving into adolescence. Debates about children's rights to know about their HIV status and treatment choices have made disclosure an increasingly important issue. Whereas disclosing an HIV infection resulting from contaminated blood products is relatively more straightforward, disclosure of perinatal transmission is more complicated as the parents also have the infection.

According to a European study (Sargent & Liebman, 1985), absence of disclosure of infection does not necessarily imply a total lack of awareness of illness. Children with HIV-infected parents may be aware of their parents' illness while they do not know the cause. Children who know of their parents' HIV status but have been asked to bear the 'family secret' experience devastating mental stress (Saffer, Sansone & Gentry, 1979). Similarly, parents of children living with HIV/AIDS tend to be overprotective and prevent their children from telling others about their illness; this may also affect the children negatively as seeking support from family and friends through sharing is a preferred coping strategy for most children (Mellins & Ehrhardt, 1994).

## **2) Emotional, psychosocial and psychiatric issues associated with HIV/AIDS**

Research has identified the association of long term psychiatric effects such as depression to HIV infection (Yirmiya, 1997). A WHO study conducted on a sample of 955 individuals from five geographical locations confirms the association of major depression to HIV infection (Maj, 1996). The special diagnostic entity for depression in DSM IV, 'depression due to a general medical condition', reflects the etiological connection between a general medical condition and depression through a physiological mechanism (APA, DSM IV). It has been suggested that in many medical conditions, an activated immune system releases cytokines that in turn affect the neurochemical and neuroendocrine systems resulting in depressive symptomatology (Weidenfeld & Yirmiya, 1996). Others have found that HIV symptomatic illness among PHAs is linked to emotional distress, depression and diminished quality of life (e.g., Perry, Fishman, Jacobsberg & Frances, 1992).

The quality of life among PHAs is also found to be affected by factors such as physical and neurological deterioration, loss of financial resources, the prospect of an early death, significant

changes in social relationships, disruption of existing relationships, and barriers to the formation of new social ties (Heckman, Somlai, Kelly, Stevenson & Galdabini, 1996). There is also evidence for an association between coping style and quality of life among people with life threatening illnesses (Brown et al., 2000). Among PHAs acute psychological distress has been associated with disease progression (Ironson et al., 1994). It should be noted that research on the association between HIV and quality of life is still in its infancy; gender issues and those related to racialized groups have been under explored. There is some evidence that gender is the single most significant predictor of distress among HIV-positive women when compared to their male HIV-positive counterparts (Kennedy, Skurnick, Foley & Louria, 1995).

PHAs with a history of sexual assault or violence also report greater HIV related illness symptoms, emotional distress and mental psychiatric disorders (Resnick et al., 2000; Kalichman, Sikkema, DiFonzo, Luke & Austin, 2002). Studies have shown a link between abuse, trauma and health problems such as opportunistic infections and AIDS-defining conditions among women living with HIV/AIDS (Kimmerling, Armistead & Forehand, 1999). More research is needed in this area, as no interventions have been tailored to meet the needs of those with HIV and a history of sexual assault.

Others have observed symptoms of posttraumatic stress, death anxiety and medication adherence difficulties among people living with HIV (Safren, Gershuny & Hendriksen, 2003). One study (Kalichman, Heckman, Kochman, Sikkema & Bergholte, 2000) found significant emotional distress and suicidal ideation in middle-aged and older adults living with HIV/AIDS. They were also more likely to use escape/avoidance strategies for coping with HIV infection, rather than positive-reappraisal coping. Suicidal thoughts were greater in men than in women. Similar findings have been reported in other studies (Flavin, Franklin & Frances, 1986; Rabkin et al., 1993; Rosengard & Folkman, 1997).

Recent advances in the medication for HIV/AIDS have contributed to the redefinition of HIV/AIDS from being a terminal illness to a chronic health condition. This underscores the important impact of psychosocial factors on the mental health of PHAs. The existential crisis and the associated emotional distress related to the epidemic were far more common during the first decade of AIDS; they are now replaced by the everyday concerns of social reintegration related to employment, income, relationships and living with a chronic condition (Heckman et al., 2002). Thus, the overall health of PHAs is dependent on their access to the basic determinants of health including housing, employment, equitable income, and access to food, etc. High socioeconomic status together with high level of cognitive functioning is associated with better

health outcomes (Vosvick et al., 2002). Low education and low socioeconomic status are markers of increased distress and poor functioning; moreover, socioeconomic status has been found to interact differently among different ethnic groups to buffer health distress (Adler et al., 1994).

Since our overall health does not exist in isolation of physical, mental, psychosocial and spiritual health, there is an increasing need for researchers, policy makers and health care providers to address HIV and AIDS with an integrated approach. Documented evidence suggested that the mental health of PHAs has significant influence on their HIV treatment adherence and outcome (Kelly, Otto-Salaj, Sikkema, Pinkerton & Bloom, 1998; Dodds et al., 2000). At the same time, studies have also identified pre-existing mental health problems such as addiction, schizophrenia, and bipolar disorder as key factors that impact negatively on HIV treatment adherence and outcomes (Stein et al., 2001; Kempainen et al., 2004). PHAs with serious psychiatric illnesses are increased risk of being incarcerated and becoming homeless, making it more difficult for them to access HIV treatment and care.

Whether mental health problems function as predictors or are mere consequences of a HIV-infection is yet to be confirmed by future research (McKinnon, Carey & Cournois, 1997). Currently, there is a lack of epidemiological data differentiating HIV cases with preexisting mental illnesses from HIV cases with subsequent neurological and psychiatric complications. Existing evidence suggests that a considerable number of PHAs have the dual diagnosis of HIV and severe mental illness; however, studies have also found acute psychological distress and psychiatric symptoms to be associated with HIV disease progression (Silver, Bauman, Camacho & Hudis, 2003).

### **3) Neuropsychiatric issues associated with HIV/AIDS and antiviral treatments**

The AIDS virus crosses the blood-brain barrier and directly affects the central nervous system soon after infection. Gradually this will result in a wide range of clinical manifestations, from subtle cognitive impairment to dementia. Consequences are either the onset of psychiatric conditions in persons with no prior psychiatric history or the complication of clinical symptoms in persons with a history of serious mental illnesses. HIV-related medical and neuropsychiatric conditions include dementia, psychotic disorders, delirium, CNS opportunistic infections and tumors, adverse effects of certain medical treatments etc. Many of these conditions involve the brain and may mimic psychiatric conditions. There is increasing evidence directly linking new onset psychosis to HIV. Psychosis may have an impact on physical disease morbidity and

mortality, but research has not yet addressed the complex relationships between psychosis and associated HIV progression and mortality (McDaniel, Purcell & Farber, 1997).

Rabkin, Ferrando, Lin, Sewell & McElhiney (2000) in evaluating the psychological consequences of highly active antiretroviral therapy in HIV positive gay or bisexual men, found that the prospects of restored health and extended survival had positively affected the mood and outlook of HIV positive people, in general. However, the laboratory markers of successful treatment were not related to mental distress. Illness stage was not a significant predictor of adjustment to living with HIV/AIDS, according to findings from Bova (2001). This and similar findings from other studies (Arpin, Fitch, Browne & Corey, 1990) are in contrast with Folkman's (1993, cited in Bova, 2001) assertion that cognitive appraisal of illness is altered at different stages of HIV disease. Gender differences might also play an important role. Whereas men may experience dramatic losses in income, status and independence at advanced stages of illness, women are often faced with poverty and powerlessness regardless of the illness stage.

Advances in HIV treatment in the last decade have led to increased survival rates of people living with HIV. In developed countries, HIV infection has become a chronic condition that requires long term management. However, current available treatment cannot eradicate HIV and long term highly active antiviral treatment regimes (HAART) are found to have side effects that may be severe enough to warrant modification. Treisman and Adam (2002) identify a number of neurological & psychiatric complications associated with HIV and AIDS, including dementia with an estimated prevalence of 15%; cognitive changes that result in difficulty with abstract reasoning, learning and information processing. Other psychiatric complications include depression, psychosis and substance abuse.

Antiviral agents have been found to be associated with neurological complication. Peripheral neuropathy which is reported in 15-50% of people with AIDS may be exacerbated or triggered by treatment with dideoxynucleosides didanosine, zalcitabine, stavudine (ibid.). Other complications associated with HIV treatment can be summarized into the following:

- **NRTI** (Nucleoside reverse transcriptase inhibitors): As NRTI can penetrate the blood-brain barrier, high doses are effective in slowing the progression of AIDS dementia. Zidovudine has been found to be effective; however, up to 5% of users report confusion, agitation and insomnia after using it for 1 year. Moreover, there is also anecdotal evidence of mania and depression. Other NRTI were found to cause headaches, malaise and fatigue (ibid., Colebunder, Hildrands, De Roo & Pelgrom, 2002; Maxwell, Scheftner, Kessler & Busch, 1988)

- **NNRTI** (Non-nucleoside reverse transcriptase inhibitors): Currently three drugs are available – efavirenz, delavirdine and nevirapine. Of the three drugs, efavirenz is found to be associated with relatively more substantial adverse effects in the central nervous system (CNS), including dizziness, headache, confusion, stupor, impaired concentration, agitation, amnesia, depersonalization, hallucinations, insomnia, and abnormal or vivid dreams. These side effects seem to subside for most patients after 6-10 weeks of usage, but for some these effects linger. While psychiatric side effects occur less frequently, they may be serious and include anxiety, depression, and suicidal ideation (ibid.) There are also a number of case reports of efavirenz-induced psychosis (Pulsen & Lublin, 2003; Garza, Durate, Garcia-Martin & Gutierrez-Casares, 2001; Blanch, Corbella, Garcia, Parellasda & Gatell, 2001) and a report of recurrence of post-traumatic stress disorder symptoms after initiation of NNRTI (Moreno, Labelle, & Samet, 2003)
- **PI** (Protease inhibitors): Compared to NRTI or NNRTI, neurologic side effects associated with PI tend to be variable and less prominent. The use of ritonavir or ritonavir with saquinavir may have more neurological symptom than indinavir (Treisman & Adam, 2003)

Hosein (2002) highlights the research findings on the long term side effect of efavirenz presented at the XIV International AIDS Conference. Researchers in Montpellier, France, interviewed 199 HIV positive efavirenz users and found that falling asleep and dizziness were more common at the beginning of therapy while other side effects were found among patients after they had used efavirenz for three months; these include: unusual or disturbed dreams (28%); problems falling asleep (23%); anxiety (22%); impaired concentration (20%); sadness (18%); agitation (13%) dizziness (12%); thoughts of suicide (10%); feeling drunk (8%) and hallucinations (6%). About 23% of the research participants reported decreased quality of life related to these side effects and 10% required treatment for them. Another study in New York found in the three months prior to using efavirenz, 27% of the study participants (n=49) who were attending HIV clinics had at least one visit to the clinic because of mental health issues, but this figure rose to 39% during the first three months when the participants were using efavirenz.

Thus far, research literature on HIV/AIDS and mental health has demonstrated that depression, and other neuropsychiatric, psychological and emotional problems are common among PHAs of all ages, particularly women PHAs and other marginalized groups. Psychosocial support, access to mental health service and basic determinants of health are important factors that affect the overall health and disease management among PHAs.

## **D) Mental health issues and needs of immigrant & refugees PHAs (I&R-PHAs)**

### **1) Systemic barriers and the mental health of immigrant & refugee PHAs**

As discussed earlier, research on the psychosocial consequences of HIV infection has mostly focused on white gay males or MSM who were the first group to be affected by the epidemic. There is a scarcity of research on the mental health issues faced by immigrant and refugee PHAs. Moreover, current research on HIV and 'minority' groups in Canada tend to focus only on the issues of HIV screening, risk factors or prevention variables such as knowledge and gender roles (Kinnon, 1999). Europe has conducted the most systematic and coordinated research work on minority populations affected by HIV, but there are few published evaluations of these research and prevention programs (Haour-Knipe, Fleury & Dubois-Arber, 1999). One of the challenges in doing this literature review was in identifying research that studied immigrants and refugees, i.e. citizenship status and other related factors. Most of the studies on HIV/AIDS and mental health issues have been conducted in the United States and the US researchers tend to use general racial or ethnic categories such as Black, Hispanic, Asian or White. Thus, this review has to draw on the reported findings on 'minority' populations with the assumption that many of them are immigrants or share similar social determinants as immigrants and refugees.

Findings from the general literature on migration and health show that immigrants and refugees experience a high level of settlement stress. Their health outcomes are influenced by determinants such as social support; pre-migration experiences; citizenship and social status; access to education, employment, adequate housing and health services; personal coping resources, community connections and social inclusion (Foss, 1996; Aroian, Noriris, Patsdaughter, & Tran, 1998; Lazaru, 1997; Nesdale, Rooney & Smith, 1997) Research has also demonstrated that discrimination and social inequities manifested are strongly associated with underemployment, unemployment, poverty and health disparity among recent immigrants and refugees (Goldberg, 2002; Grignon & Laryea, 2001; Li, 2003; Boyd, 1984; Pendakur & Pendakur, 1996).

The second wave of HIV infection in the 1990s included greater numbers of poor people and people from racial/ethnic minority groups (Moore et al., 1999). There is increasing evidence that migrant populations, in general, approach both HIV testing and HIV care much later than their native cohorts (Haour-Knipe, 1997). The delay in testing and seeking treatment is likely related to their preoccupation with other priorities such as employment and settlement. For example, people who have fled from war in their home countries may experience HIV as a far-distant

threat that does not need immediate attention, compared to other urgent problems (Haour-Knipe, Fleury & Dubois-Arber, 1999).

The acculturation hypothesis suggests that risks of disability and chronic disease morbidity in immigrants augment the increased length of residency in the new country. The HIV epidemic represents one of the greatest challenges to infected individuals, their families and the systems of care because of the complexities associated with behavioral risk, disease transmission and consequences. These challenges become even more profound as racialized immigrants and refugees are faced with racial and ethnic disparities in the health care and the social welfare systems. There is evidence of an association between identified objective and subjective experiences of oppression and HIV risk behavior (Roberts & Miller, 2004).

For HIV infected families in Europe, an important barrier in accessing health services is the social marginalization resulting from poverty, parental drug-use and/or ethnic minority status (European Collaborative Study, 1998). In the US, a higher rate of HIV infection is observed among Black Americans (Fitzpatrick, McCray & Smith, 2004). Institutional racism is suggested as a likely explanation for the finding that being Black in the US was a potent predictor for receiving inadequate HIV care, even when economic, health, social and psychological variables were controlled for (Andersen et al., 2000). One study (Duran et al., 2000) identified American Indians with HIV/AIDS as having unmet needs including mental health and social services related to housing, food, clothing and transportation.

In London, Black Africans were nearly 3 times less likely to be referred for mental health assistance than the general population of patients; they were also more likely to be infected with HIV at the time of referral (Fitzpatrick, McCray & Smith, 2004). Another London study reported on the experiences of young female asylum-seekers, who were caring for their refugee parents living with AIDS and younger siblings; these young women suffered in isolation; they experienced intense distress and felt vulnerable because of their refugee status and the indifference of the host nation in dealing with their needs (Chinouya-Mudari & O'Brien, 1999 as cited in Schoepf, 2001).

The cultural perception of HIV/AIDS in any given society is a result of complex social, political and economic dynamics. Although there was a clear link between the spread of HIV and social inequality, the blame was put on individual behaviors or the cultural differences of groups (Sobo, 1999). The construction of HIV/AIDS as a disease in many parts of the world has based on ideas of deviant behaviors and moral differences. Many of these ideas stem from, reproduce and perpetuate social hierarchies based on gender, sexuality, race, class and ethnicity, etc.

They also reinforce stigmatization and discrimination; for example, Haitians were denied housing, dismissed from jobs and required to undergo tests to enter the US; African students were targets for violence in Europe (Osman Kabia, 2000 as cited in Schoepf, 2001).

There is strong evidence that discrimination, social exclusion and poverty contribute to the increased risk of HIV infection and poor management of HIV/AIDS. While there is a scarcity of Canadian research on immigrants and refugees living with HIV and AIDS, evidence from research on other marginalized groups, such as the Aboriginal peoples demonstrate this connection. In Vancouver, for example, Aboriginal injection drug users (IDUs) are becoming HIV positive at twice the rate of non-Aboriginal IDUs; HIV/AIDS is also disproportionately affecting Aboriginal youth and women (Craib et al., 2003). It has been suggested that the overrepresentation of Aboriginal IDUs in Vancouver is related to injection drug use as a coping mechanism against the effects of discrimination, poverty and social dislocation (BC Aboriginal HIV/AIDS task force, 1999).

## **2) Immigrant women living with HIV/AIDS**

Relatively little is known about the psychological distress experienced by immigrant women living with HIV/AIDS. As stated earlier, most of the studies on HIV/AIDS and mental health issues have been conducted in the US and the researchers tend to use general racial or ethnic categories such as Black, Hispanic, Asian or White in these studies rather than citizenship status; thus, making the unique experiences of immigrants and refugees inaccessible. However, as racialized women PHAs often share certain commonalities, this report draws on the findings of existing studies in order to understand some of the issues faced by immigrant women PHAs.

Research suggests that women PHAs tend to belong to marginalized groups, be single, under-educated, and living in urban areas with limited social and economic resources (Silver, Bauman, Camacho & Hudis, 2003). These social circumstances compromise their physical and mental health. In the US, Black and Hispanic women are disproportionately affected by HIV/AIDS (Amaro, 1995). It has also been observed that there is an increased prevalence of trans-generational patterns of psychiatric problems, substance abuse and violence in families of women with HIV/AIDS (Dodds et al., 2000). One study shows high rates of psychiatric and affective disorders among poor women of color in an inner city clinic, with many meeting criteria for mood disorders and substance abuse disorders (McDaniel, Fowlie, Summerville, Farber & Cohen-Cole, 1995). For poor racialized women who have limited access to and trust of health care services, HIV/AIDS care might not be their priority need.

For immigrant and refugee women, other life events related to the migration and settlement processes may have significant influences on their mental health; thus, their HIV-status alone cannot be used to explain their mental health status. Other struggles such as malnutrition, infections, trauma, violence and displacement also contribute to their mental health. One study indicates that women of ethnic minority women are at a greater risk for both HIV infection and PTSD (Martinez, Israelski, Walker, & Koopman 2002).

African American women's psychological reactions to learning about their HIV-status should be understood in the context of higher prevalence of HIV/AIDS in the male population. Also, being historically stereotyped as less "feminine" to their White counterparts, the African American women's seropositive status could be viewed as reflecting a marked departure from their feminine gender role; this departure brings forth a unique set of psychological reactions in a community which is already struggling with complex social discrimination. The additional demands generated from these complex reactions and interactions within the community and in relation to the larger society put African American women at increased risk of poorer health outcomes. At the individual level, factors such as the couple's relationship status, the partner's reactions upon learning the woman's seropositive status, history of victimization within the relationship, decision about future pregnancy and parenting issues all contribute to the mental health of African women PHAs (McNair & Prather, 2004).

Miles et al. (1997) found feelings of stigma, self-perceptions of health and physical symptoms to be the best predictors of depressive symptoms in HIV infected mothers, whereas personal characteristics such as maternal age, education and family structure were the least predictors. Silver and his colleagues (2003) found that physical restrictions in performing daily activities and child care were associated with greater distress in a group of HIV-infected mothers who mostly belonged to minority groups. Low education was also a marker for psychological distress. Although social support was a protective factor, it only had a modest relationship to distress indicating that the support system may be less efficient in relieving the symptoms of HIV infected mothers.

Moore and his colleagues (1999) explored depressive symptoms among the HIV infected in four cities in the US, their samples including minority groups of African Americans and Hispanics. The study found that most of the HIV-infected and at-risk women in this study were experiencing significant dysphoria. Though their symptomatology could not be categorized under clinical depression, the dyphoria is worth attention because of its interference with daily functioning,

medical adherence and increased risk of substance abuse (Burack et al., 1993; Markowitz, Tabkin & Perry, 1994; Kelly et al., 1993).

The Moore study (1999) indicates a strong relationship between poverty, mental health and physical health and suggests the importance of addressing the root causes of social and psychological distress in women that put them at risk of poor health. Income was found to be an independent predictor of depressive symptoms in both infected and uninfected women, and ethnicity was a predictor of depression in infected women. The investigators also find a significant race/ethnicity effect on depressive symptoms among infected women, with white women reporting more symptoms than black women and Hispanic women reporting the most of all. Similar patterns of race/ethnicity effects on depression have also been reported by Fleishman and Fogel (1994). Further research is needed to learn more about mediating factors between race/ethnicity and depression, and about race/ethnicity-dependent coping mechanisms in dealing with HIV.

In terms of spirituality, one study conducted predominantly on minority HIV positive women finds no association between religious coping and the quality of life. It identifies denial as a key factor related to poor quality of life, whereas cognitive coping was related to improved quality of life (Weaver et al., 2004). The study also suggests that coping strategies, by either lessening or heightening perceptions of life stress, may influence the quality of life in PHAs. However, another study done Musgrave, Allen & Allen (2002) finds spirituality to be an important dimension of coping in HIV positive African American women in another study (2002). Further study in this area is needed for us to understand the relationship between spirituality and mental health among PHAs of diverse backgrounds and religious beliefs.

### **3) Multiple marginalities: Immigrant and refugee LGBTQ, IDUs & sex workers living with HIV or AIDS**

As discussed earlier, there is a lack of research addressing the mental health issues of immigrants and refugees living with HIV or AIDS. When it comes to research on immigrant and refugee LGBTQ: lesbians or women who have sex with women; gay men or men who have sex with men (MSM), bisexual men and women; transgendered or transsexual people; queer youth; injection drug users (IDU) and sex workers, even fewer published studies exist. The level of ambiguity to the extent of inclusion of marginalized populations in research studies speaks to the experience of marginalization, discrimination, and multiple oppressive forces these populations experience in society (as discussed in the Introduction section).

## Method of literature search

Two methods were used to determine the gaps in research and to obtain information on the mental health issues of immigrant PHAs in the marginalized populations.

- i) Comparative Search: This general search allowed for a comparison of the number of research articles on each marginalized population and how it compared to the number of articles on the general population. The social science PsychINFO database offered the most articles on psychosocial issues pertaining to PHAs. This method revealed the amount of current research, and the gaps in each population. Keywords: [immigrants or ethnocultural communities, or minority groups] & [acquired immunodeficiency syndrome] covered the widest cross section of articles related to immigrant/refugee & HIV/AIDS. Out of 156 articles, 31 related to PHAs of colour (Appendix I- A).
- ii) Focused Search: A search of each population was done by using various databases, libraries, and websites to find literature on the mental health issues of each population. The databases used: Medline, PsychINFO, Canadian Business Current Affairs. Websites: AEGIS.com, AIDSline. Libraries: ACT library, CATIE, University of Toronto Catalogue. Journals: CERIS, and different journals with foci on ethnic studies. Limited time and expediency only allowed the review of articles found on ejournals/e-resources however an effort was made to gather obvious studies on the marginalized populations when found in other forms.

Using the PsychINFO database, a comparison search was done to assess the extent of research on the mental health issues, needs and experiences of immigrant PHAs in the marginalized populations. A search using the key words: minority groups, ethnocultural communities, immigration & acquired immunodeficiency yielded 156 articles from 2000 to 2004. Out of the 156 articles, thirty-one (19%) are related to PHAs. Only 2 of these articles directly researched immigrant PHAs. The majority of the articles were US based with only one Canadian article (Appendix I-A). This comparison in the number of articles per population clearly shows the inequity and lack of research on queer youth, injection drug users, sex workers, Transgendered PHAs and on WSW, as highlighted below:

- 32% General population: men and women (all heterosexual)
- 19% MSM (gay and bisexual)
- 25% Women (heterosexual)
- 19% with youth (5 heterosexual, 1 MSM)
- 2 articles on injection drug users (1 heterosexual, 1 MSM)

- One on sex workers
- 0% on WSW
- 0% on Transgendered

The articles can be classified into four broad categories: the mental health experience of PHAs, prevention, treatment, and health services. Some articles overlapped in research areas. Among the marginalized populations MSM was comparatively more researched. Overall the breakdown of the comparison search was:

- 35% Mental health - psychosocial, socioeconomic, and systemic barriers related to mental health of PHAs. (Mostly to do with MSM)
- 35% Prevention - education strategies to promote safer sex among PHAs
- 20% Treatment - concerns the adherence of PHAs to drug therapy
- 8% Service - involves the (under)utilization of services and programs by PHAs

Moreover, there was very little Canadian content among the research on immigrants/refugees, and on marginalized immigrant/refugee PHAs. In the comparative search only 1 out of 156 articles was Canadian based. A search on the database, Canadian Business and Current Affairs, on immigration and AIDS yielded 10 sources (searches with other keywords yielded the same articles). Only one article was peer reviewed and concerned AIDS prevention outreach of SE Asian MSM in Toronto (13), while the remaining articles mainly discussed legislation around mandatory HIV testing of immigrants.

The following subsections deal with the mental health issues, needs and experiences of marginalized immigrant or refugee PHAs.

#### **4. a Immigrant and refugee IDUs living with HIV or AIDS**

There is a scarcity of research on IDUs within the immigrant and refugee populations. However, studies of the general IDU population identify history of sexual abuse, violence, poverty, inadequate housing, racial and social discrimination, unemployment and existing psychiatric conditions as factors that contribute to their HIV status and general state of health (Hilton, Thompson, Moore-Aempsey & Janzen, 2001; Braitstein et al., 2003). A study on 202 HIV positive women in New York shows that patients who were older, unemployed or who had a history of drug use reported lower health-related quality of life than those who were younger and had no history of drug use (Smith, et al., 1996).

Other studies show that immigrant or refugee IDUs are most likely to experience multiple social and systemic oppressions such as racism, poverty, social isolation and police targeted discrimination. A study on women injection drug users who have sex with women (WSW) found

that the experience of racism, in addition to the stigma of drug use, contributed to the higher rates of HIV/AIDS (Rotheram-Borus, Lee, Zhou & O'Hara, 2001).

Another study of Vietnamese immigrant drug users in Sydney, Australia found that 30% were HIV positive and that 60% shared needles, and practiced unsafe sex. Linguistic barriers and the lack of culturally competent programs were linked to the lack of knowledge of safe practices and education around HIV/AIDS prevention (Kwakawa & Ghorbrial, 2003). Although the degree of stress, depression, and social isolation that IDUs experience has not been explicitly explored in the studies examined, it is implicit in the discussion around barriers and the causes of high seroprevalence. Since the stigma of injection drug use is very intense both in society and within ethnocultural, women, and LGBT communities, stress and mental health problems related to discrimination and social exclusion are common (ibid.) Moreover, counseling was identified as one of the highest rated service needs among female IDUs (Nemoto, et al., 2004).

#### **4. b Immigrant and refugee sex workers living with HIV or AIDS**

There is a lack of direct information on immigrant/refugee sex workers who are HIV+ in a Northern American context. However, studies on IDU populations often refer to groups of people who engage in sex work, and with the lack of direct studies done on sex workers some observations can be made on their mental health issues. This in no way suggests that these groups are one and the same, or that intra-group distinctions do not exist. The following information concerns the mental health issues of sex workers who engage in intravenous drug use.

One study on transgendered male-to-female (MTF) in San Francisco described the inability to negotiate safe sex in their work and in their sexual relationships. Over 50% of the research subjects (n=332) were or had been sex workers due to lack of employment. They experienced low self-esteem, and a high level of depression due to the experience of multiple stigmas. A cycle of depression, drug abuse, and engaging in high risk sex work including receptive anal and unprotected sex (Leung & Galtic, 2001)

#### **4. c. Immigrant and refugee transgendered people living with HIV or AIDS**

Only one article was found that clearly spoke to the mental health issues of transgendered immigrant PHAs. This study involved 332 male to female transgendered individuals (MTFs) in San Francisco and it correlated ethnic and racial differences with HIV/AIDS rates in African American, Latina and Asian Pacific Islanders subjects (Leung & Galati, 2003). Most MTFs suffered from lack of employment, housing and homelessness related to transphobia,

discrimination, and stigma around injection drug use. Many transgendered people of colour experienced discrimination and were afraid to seek health services, suggesting the need for sensitivity training among service providers and the general public, and culturally competent health programming.

Some MTFs revealed the use of sex to affirm female gender identity with numerous casual sexual encounters, and the use of drugs to deal with depression and sex work. Latinas were more likely to engage in higher sex risk (unprotected sex and sex under the influence of drugs); Asian Pacific Islanders were more likely to engage in safer sex. This was linked to socioeconomic factors with more Latinas living in poverty.

#### **4. d. Immigrant and refugee MSM living with HIV or AIDS**

MSM experience racism, homophobia, and AIDSphobia in the dominant and queer community. The impact of this affects many areas of their lives, including their mental and physical health (Kang, Rapkin, Springer & Kim, 2003; Kwakwa & Ghobrial, 2003; Thompson, Blankenship, Selwyn & Khoshnood, 1998). Anti-immigrant discrimination and the stereotype of Asians as carriers of contagion intensify social isolation and fear of violence (Ibanex-Carrasco, 1996).

In a study on undocumented immigrants in New York, settlement issues such as acculturation, finding work, learning English, and losing or being away from social and familial support networks were critical issues (ibid.). A Canadian study on health risk behavior in HIV positive youth, gay and bisexual males scored low on a quality of life scale. They scored higher in distress scales, were more likely to practice unsafe sex, and unclean needle use. They were also more likely to have higher rates of seroprevalence, multiple partners, and risky drug use (Murray & Adam, 2001).

The high degree of unemployment, due to illness, lack of credentials and language barriers, compromised their ability to work and financially support themselves and their family. This contributed to a sense of being a burden to family and society. Moreover, the decision to disclose HIV/AIDS status is a critical cause for concern among many MSM in different ethnocultural communities. Among Southeast Asian men disclosure, was intimately tied to “coming out of the closet” about being gay. Among Asian undocumented immigrants, fear of disclosure is greatly increased. A study compared undocumented immigrants with status immigrants and found lower levels of disclosure and higher levels of stress (Kang, Rapkin, Springer & Kim, 2003; Ibanex-Carrasco, 1996). Among Latino gay men, a study found a correlation between high levels of social isolation with low degrees of disclosure (Thompson, Blankenship, Selwyn & Khoshnood, 1998).

Two studies of Southeast Asian gay and bisexual men found that the participants commonly express shame about their HIV status. This may be related to the perception that immoral behavior is the cause of AIDS. Feelings of guilt over having family worry about them and bringing shame to the family cause may participants to withhold information about their illness, sexual orientation, and/or medical needs (Kang, Rapkin, Springer & Kim, 2003; Ibanex-Carrasco, 1996). Having to keep their HIV status from family and friends increases the likelihood of social isolation and thus may also negatively affect their mental health.

#### **4. e. Immigrant and refugee WSW**

There are many reasons attributed to the lack of HIV/AIDS research on WSW. They are understudied because of the persistent notion that lesbians are not vulnerable to HIV/AIDS (Leung & Galati, 2001). This occurs even though there is increasing attention given to the diversity of sexual behaviors among WSW which include sex with heterosexual and MSM (Rotheram-Borus, Lee, Zhou & O'Hara, 2001) As well as injection drug use, there are other behaviors for HIV transmission. In 2002, the first case of lesbian transmission was documented between two lesbians sharing sex toys when one of them was HIV positive (Kwakawa & Ghobrial, 2003).

In addition, lesbians and bisexual women (with female partners) are often not recruited for study. Also, data collection such as questionnaires with structured questions do not allow for disclosure by women concerning the gender of sexual partners which contributes to the invisibility of WSW in research studies. Fear of disclosure is another reason for hidden participation. Homophobia and heterosexist methodology in research studies are unsafe environments for WSW to communicate their sexual orientation, identity, or sexual practice (Rotheram-Borus, Lee, Zhou & O'Hara, 2001)

The implications for immigrant PHA women who have sex with women are critical. It means that their psychosocial experiences are unknown. What are their mental health issues? How specifically do socioeconomic factors affect their mental and physical health? What are the particular struggles and barriers they experience in seeking community and treatment services?

#### **4. f. Immigrant and refugee Queer Youth**

Denial of HIV status is a common experience of testing positive. This fear of rejection from parents, friends, and peers can begin from initial diagnosis and last for extended periods. In a study of LGBT youth in Toronto, it found that lesbians often used denial as a coping strategy. Denial caused them to avoid other HIV positive people. (Poon, Ho & Wong, 2001).

Isolation, loneliness and lack of social networks are common themes for LGBT youth PHAs. They often do not feel accepted because they are queer and HIV positive. Many youth hide their HIV status and queer identity from family and friends while some isolate themselves in the company of HIV- queer youth because they do not want to be reminded of their HIV status. They also fear blame and condemnation from other gay teens because they should know better about safer sex. This impacts their self-esteem and self image (ibid.).

Racism and anti-immigrant sentiments are barriers that a young immigrant or refugee PHA negotiates as well as the other challenges of being queer. Although no explicit information concerns this in research on queer youth some refer in passing to the increased marginalization of ethnic/racial factors. In one study on risk behavior in youth living with HIV, males who had sex with other males were more likely to practice unsafe sex and drug use by sharing unclean needles (Murray & Adam, 2001)

### **Literature Review Conclusion**

Despite a scarcity of research literature that focuses on the mental health and service needs of I&R-PHAs in Canada, this literature review has drawn on literature from studies of the general PHA populations from the US and other countries to formulate a picture of the mental health needs and challenges faced by I&R-PHAs. Based on these findings, it is apparent that mental health care and services that address the intersecting dimensions of mental health, HIV and migration/settlement are essential for effective HIV treatment and disease management among I&R-PHAs.

Moreover, this review has identified a number of challenges and current research gaps:

1. In terms of HIV and AIDS surveillance data, limited and incomplete data on ethnicity and HIV or AIDS have been made available only since 1998; the lack of complete data makes it hard to derive a clear picture of how the different immigrant and refugee communities are affected by HIV and AIDS.
2. While a substantial number of studies have been conducted on mental health and HIV/AIDS, most of these studies are from the US. In two comprehensive literature reviews funded by Health Canada on 'immigration and health', both the researchers identified that there is a lack of Canadian studies on immigrants, refugees and HIV (Kinnon, 1999; Hyman, 2001). Of the limited studies that exist, most of them focus on screening, prevention and behavioral risks related to gender roles, cultural issues and other social factors.

3. The research on HIV/AIDS has a heavy biomedical emphasis and a largely individualistic bias in its approach that can be problematic, as different cultures and specific sexual cultures and subcultures, even within the industrialized Western societies, have radically different understandings of sexual expression and practices (Parker, 2001; Schoepf, 2001). An important reframing of research on sexuality in relation to HIV/AIDS has been in viewing the body as both a symbolic and a material product of social relations (Parker, 2001).
4. Psychological health is perceived and determined by one's culture, and behaviors related to HIV transmission and management is influenced by the norms, values, practices and ways of life in a particular individual's culture. Different ethnic and cultural groups may view AIDS and other risk factors in ways that are different from the dominant culture. Programs that are proven to be effective and successful are not cultureless, though they are often presented as culturally generic phenomena (Beatty, Wheeler & Gaiter, 2004). But there is a lack of theory or empirical evidence to guide culturally sensitive research and practice (Roberts & Miller, 2004).
5. Another difficulty was identifying the ethnic or cultural background of the research populations. General terms familiar in an American context such as: Latino, Hispanic, Asian & Pacific Islanders, minorities, and minority women/men/youth were often used. Although this facilitates some definition of research populations it also acts to erase and amalgamate distinct cultural and ethnic groups. A common practice was to group subjects by race; in many US based articles, the category of "other" was used to contain ethnocultural groups which were not African American or Hispanic; an example of the gross generalization of groups of people is a study conducted on 332 homeless subjects divided into "blacks and whites" (Louie, Krouskos, Gonzalez & Crofts, 1998).
6. The interpretation of cultural meanings is important in designing more culturally appropriate prevention programs, i.e., ones that take into consideration the collective character of sexual meanings in a given culture. Culturally appropriate behavioral and mental health interventions and tools should be developed and applied, if we are to gain success from the advances of medical and technological methods in preventing and treating HIV/AIDS. Another issue related to research and culture is the problem of combining data along racial and ethnical lines, which may result in erroneous conclusions. Exploring the similarities as well as the differences by race and ethnicity will help to disentangle these categories from those of culture and socioeconomic status (Bova, 2001).

7. Because of the large number of variables having a potential effect on the mental health of HIV-infected individuals and families, we need large studies with extensive data collection to get a complete picture. But in-depth qualitative studies with a longitudinal design could also be of interest and are important to better understand the unique factors related to vulnerability in different populations (Forsyth, Damour, Nagler & Adnopo, 1996). Much of the research on barriers to care does not systematically assess the direct experiences of PHAs. Action research strongly suggests that people often have a great deal to tell us about their own situations (Stansbury & Sierra, 2004). But a systematic assessment of the direct experiences of PHAs is scarce (Heckman et al., 1998).
8. One general point of criticism on research related to infectious diseases is that they overlook issues of inequality and poverty (Stansbury & Sierra, 2004). There have been suggestions that a HIV infection, with time and adaptation, does not cause any greater distress in individuals than other serious diseases (Pergami, Gala, Burgess, Invernizzi & Catalan, 1994; Perry, Jacobsberg & Fishman, 1990). Though the onset of HIV symptoms or an AIDS diagnosis can increase the distress, extreme psychological reactions are found to be rare, except in people with a history of psychiatric disorder (Brown et al., 1992; Perkins et al., 1994).
9. Although the reality of I&R-PHAs reflects multiple and intersecting dimensions of their existence, including gender, race, class, citizenship, socioeconomic status, sexuality, physical and mental health status and others, current research literature on HIV does not reflect this reality. Thus, a search of the literature will only yields studies on HIV and sexual orientation, or HIV and gender, or HIV and race with very few studies addressing multiple dimensions. When the literature search is limited to mental health and I&R-PHAs, the challenge becomes even greater. Lack of information made it difficult to ascertain the citizen status and country of origin of research subjects. In the majority of literature demographic information such as citizen, immigrant, or refugee status was not collected; however some references to acculturation, language usage, and passing references to “race/culture” and “minority” status of the subjects indicated the research subjects were nonwhite, and possibly immigrant or refugee PHAs.
10. While immigrants and refugees as two general groups have been marginalized in research, diverse groups within the immigrant and refugee populations, such as immigrant and refugee LGBTQ, lesbians or women who have sex with women (WSW), gay men or men who have sex with men (MSM), bisexual men and women, transgendered or transsexual

people, queer youth, injection drug users (IDU) and sex workers, are further marginalized. Research biases lead to the routine exclusion of sexual orientation and partner gender in HIV research. Out of thirty-one relevant articles pertaining to immigrants, refugees and HIV identified through a search on PsycINFO between 2000 to 2004, twenty (65%) did not include sexual orientation and/or sexual partner as a demographic category (Appendix I). There is an assumption that the subjects are heterosexual, and that ethnocultural populations are heterosexual. The 8 articles that did include sexual orientation and gender of sexual partners involved MSM. WSW are commonly not identified in studies, and not solicited for HIV/AIDS research because of the persistent notion that lesbians and lesbian sex is low risk (Nemoto, Operario, Keatley, Han & Soma, 2004).

11. Spirituality appears to be largely overlooked in current HIV/AIDS research (Somlai & Heckman, 2000). In general, psychological beliefs such as meaning, control and optimism were shown to be protective of physical and mental health in men infected with HIV (Taylor, Kemeny, Bower, Gruenewald & Reed, 2000). A sense of meaning, which can be closely related to one's religion and/or spirituality, is an important aspect of understanding the consequences of chronic disease. Religious commitment is found to improve one's ability to cope with mental and physical illness (Matthews et al., 1998). Among PHAs, prayer and formal religions were more frequent than in their non-infected counterparts (Somlai et al., 1996). Spiritual activities such as meditation, imaging, and prayer were closely linked to perceptions of well-being among long term survivors of AIDS. The emergence of new spiritual meanings, incorporating the illness into one's self-concept of spiritual being and a spiritual understanding of life are suggested as important spiritual themes among PHAs.

This literature review represents an attempt to link research findings, some of which are ambiguous, on the different dimensions of HIV/AIDS, mental health and migration/settlement into a coherent picture. Because of the gaps in both topics and methodology, the overall picture presented is incomplete. There remain many questions: What are the experiences of I&R-PHA in accessing mental health services in Ontario or Canada? What are their coping strategies in dealing with multiple losses, uncertainty and marginalization? How do they manage or overcome the numerous sets of stigma and challenges that face them? How do the biological, social and spiritual aspects of living with HIV and AIDS affect their physical, mental, emotional and spiritual health and vice versa? What are the key elements of holistic and inclusive HIV/AIDS care for I&R-PHAs? What does a comprehensive and integrative HIV/AIDS care model look like? More research that explores these topics in a Canadian context is absolutely

critical, if we want to succeed in stopping the HIV/AIDS epidemic and promoting the health and quality of life among all PHAs.

## **Part II: Program Scan**

### **Introduction**

As the published literature on mental health issues and needs of immigrant and refugee PHAs in Canada is scant and there is a gap in understanding the accessibility and utilization of mental health services by this population, a program scan was performed to acquire a glimpse into the current mental health services for immigrant and refugee PHAs in the Greater Toronto Area. Due to time and resource constraints, only a 'scan' was performed. The findings, by no means, represent a comprehensive analysis; however, it does identify the need for evaluation research in this area.

#### **A) Existing services for immigrant/refugee PHAs in the Greater Toronto Area**

Currently, I&R-PHAs who are connected with AIDS service organizations (ASOs) appear to have the best chance of being connected to other service organizations that serve their non-HIV needs. This program scan aimed to explore the potential experience of I&R-PHAs who are not connected to ASO. Thus, instead of drawing from resources like *A Guide for People living with HIV or AIDS*, this program scan drew from a common non-HIV/AIDS related directory, *the 211-Toronto* which is accessible by phone, at local libraries and on the internet. The use of the 211-Toronto Directory of community service and program information yielded 10 agencies stating that they offer mental health services to immigrant PHAs in Toronto. In varying degrees these 10 agencies offer a wide range of services from settlement issues, legal clinics, primary medical care, mental health services, employment programs and health promotion services (STD, Birth Control, and HIV/AIDS information). Most offer services in different languages and some include language interpretation. As this is not a research study, but a program scan and the purpose is to acquire a glimpse of mental health service accessibility and availability, the names of the specific agencies scanned are replaced by general labels that describe the types of services (refer to Appendix II-A. 211 directory - Community Health Agencies).

In order to determine the accessibility of these agencies to I&R-PHAs an email was sent to each agency requesting help. The email was based on a fictional service seeking scenario requesting counseling for a Vietnamese immigrant female PHA who does not speak English and is experiencing depression. This method was used to determine two factors in service accessibility: a) whether services to I&R-PHAs were available as advertised in the 211-toronto directory; and b) if no service was available, whether the initial agency contacted would make a referral to the appropriate agency.

In a period of 21 days, three out of the ten agencies responded immediately to the information request. Of these three, two offered referrals to other agencies with Vietnamese language services and the third agency stated that counseling services were not available in languages other than English. The remaining seven agencies did not respond.

Follow up of the secondary referrals lead to other referrals (Appendix II-B). The majority of these agencies gave a second referral that did not offer the appropriate service either because they did not have the language service, or because they did not offer "HIV counseling". In one case, an agency provided a referral that lead to eight other referrals, eventually the appropriate service was found (Appendix II-C). In all, two agencies in Toronto stated that they were able to offer mental health services to a Vietnamese speaking immigrant PHA; assessment of the type and quality of services to be provided by these 2 agencies (re: AIDS-positive, Anti-homophobic, Anti-oppressive, etc.) are beyond the scope of this scan

## **B) Accessibility of services and programs**

Although this by no means is a comprehensive assessment, some implications can be made. At least two community health (CH) agencies were able to respond to a request for mental health service, and at least one CH agency, although advertising accessible services to some non English speaking immigrants, was not able to do so, it only offered its HIV/AIDS support services in English.

As for the lack of response from the remaining seven agencies, many reasons can be attributed; however this complicated service seeking experience, with numerous misinformed referrals for an English speaking person, playing a supportive role, was quite difficult. The key question is: how would a non-English speaking immigrant or refugee fair in her efforts to seek help for herself?

In addition, the nature of seeking assistance over the phone is a critical area of study. Accessing help by phone for information and/or services by speaking to a receptionist, intake worker, counselor or service provider, or through an automated phone system is a critical entry into the service seeking process. In the agencies surveyed, there was an even number of agencies with staff to answer calls, and agencies with recorded messages providing different information/personnel options. Only three agencies had multi-lingual services (two were intake workers and the other, an answering service greeting callers in English and in three different South East Asian languages). For an immigrant/refugee PHA with limited or no English this is a critical point of entry into accessing information and services. Passing this first hurdle could be a lengthy and stressful process.

Also, the manner in which calls for service are received affects the degree of accessibility. The tone and sensitivity of the receptionist, intake worker or counselor is very important. Three general responses to help seeking calls found in this scan were: rushed and expedient, attentive and sensitive, or dismissive. This impacts the ability to access information and services, particularly for a caller with limited or non-English speaking skills, who feels vulnerable about disclosing her HIV/AIDS status, and/or self-conscious about seeking help. Out of 10 agencies contacted, 4 agencies responded in a rushed and expedient manner, 5 attentive and sensitive, and 1 agency was dismissive and possibly AIDSphobic (Appendix II-D).

In conclusion, there is a considerable lack of knowledge among the agencies contacted. Considering the agencies that responded, on average it took three referrals to find an appropriate agency that could offer mental health services to a Vietnamese speaking immigrant PHA. It took considerable time, effort, and patience, as well as, an understanding of the social service delivery system, and an ability to communicate in English in order to find two agencies that provide mental health services. At the end of the process the researcher was left with a general feeling of how unlikely, and difficult it would be for a non-English speaking person to access services over the phone or by email.

Finally, for the immigrant/refugee PHA, there are considerable barriers in accessing mental health services. They involve linguistic inadequacies in the Toronto health service system, a lack of sufficient mental health and HIV/AIDS services for immigrant/refugee PHAs (only two agencies were found over a 1 month period). One of these agencies had a waiting list, and it would take some time to see the Vietnamese counselor unless the client has a psychiatric illness.

### **C) ASOs across Canada**

Twenty-five ASOs across Canada were contacted by email with the same request. At least one ASO in a major city in each of the ten provinces was identified. Currently, only one has responded with the appropriate intake worker to contact (who was on holiday). Time did not permit a further exploration of how accessible these agencies are to immigrant/refugee PHAs.

### **D) Service and program gaps in the Greater Toronto Area**

The service and programs gaps for immigrant and refugee PHA are summarized in the following:

- **Lack of coordination:** There is a lack of coordination among agencies in regard to knowledge of other agencies, services and programs to immigrants and refugee PHAs. In some agencies, the intake worker was unprepared, and ineffective in assisting: one agency

suggested calling the 211 directory (which had referred her agency). Most agencies surveyed gave out erroneous referrals.

- **HIV/AIDS awareness and training:** There was a lack of understanding of the needs and concerns of an immigrant/refugee PHA; for example some agencies were not sensitive to the possible need for anonymity of PHAs.
- **Language services and interpretation:** Some of the ASOs and community health organizations were not ready to deal with a client who did not speak English. The immediate response was to make a referral to an ethnocultural community agency (Appendix II-E).
- **Anti-AIDSphobia training:** In at least one case, there was an obvious reaction to a request for help for a PHA. A Vietnamese speaking counselor reacted dismissively to the request for help and information. He was abrupt on the phone and immediately wanted to redirect the call, initially, back to the intake worker, then to an inappropriate agency (Appendix II-C).
- **Sensitivity and compassion:** There is a need for sensitivity and compassion among service providers. For the immigrant/refugee PHA, help seeking involves negotiating a myriad of social factors, as well as the vulnerability of disclosing their HIV/AIDS status, and the fact they need mental health services (Appendix II-C)
- **Flexibility around service catchments:** some agencies made referrals that were a considerable distance away, either from a of lack of concern for where the client lived, or by the need to adhere to service catchments
- **More mental health services and programs for immigrant PHAs:** Only two agencies were identified that provided counselling and support services for immigrant PHAs. Out of the two agencies, one agency could not offer immediate counselling service and has a waiting list
- **Consideration and provision for undocumented PHAs:** On two occasions community health agencies asked if a health card was available; this presents difficulties for PHAs without documents, or have not been able to attain them. In addition, recent immigrants who have not been in Canada for a three month period may not be eligible for a health card
- **Need for in-depth research and audit:** There is the need for in-depth evaluation research and the development of an auditing system and mechanism to determine the accessibility of service and programs for immigrant PHAs with a range of mental health needs.

## **Program Scan Conclusion**

Currently, ethnospecific ASOs in Toronto are the key agencies serving immigrant and refugee PHAs. However, most of these agencies have limited resources due to under-funding; in addition, their funding sources set limits on the types of services (focus on HIV prevention, education and HIV support) they must provide. While they are able to provide emotional and social support, complex mental health or psychiatric care of PHAs will be beyond their scope and capacity based on their current resources. Thus to reduce service gaps for immigrant and refugee PHA, research on existing services beyond ethnospecific ASOs is needed to identify potential opportunities for collaboration and strategies that improve coordination, accessibility effectiveness and efficiency of mental health services for I&R-PHAs.

## **Part III: Community Focus Consultation**

### **Introduction**

In the summer of 2004, with funding from OHTN, ACAS and CAAT conducted two focus groups, one with immigrant and refugee PHAs living in the Greater Toronto Area and one with service providers working in the HIV/AIDS and community health sector. The purpose of the focus groups was to identify mental health issues faced by I&R-PHAs, their need for mental health services, and to identify research priorities in this area.

### **Research participation**

Participants were recruited through community outreach through ASOs, existing community distribution email networks and the CAAT membership agencies. The recruitment method serves the current purpose within the time and resources constraints.

- a. I&R-PHA Focus Group: A total of 10 PHAs from the five ethnospecific communities served by CAAT were recruited for the focus group. Seven out of these 10 PHAs attended the focus group: one registered female PHA could not attend due to hospitalization; two registered male PHAs did not attend due to last minute demands. Of the 7 focus group participants, 2 were females and 5 were males. Five of the PHAs speak a language other than English or French at home; 1 PHA speaks English at home since the language used in the country of origin was English; and 1 PHA speaks French at home. All participants are currently connected to a community ASO specific to their ethnocultural backgrounds and 1 or 2 umbrella organizations such as People With AIDS and AIDs Committee of Toronto. Some have also identified that they are connected to primary care, hospitals and hospices.
- b. Service Provider Focus Group: A total of 10 service providers affiliated with primary care, hospice care, and ethnospecific community ASOs attended the focus group. Two other service providers gave their thoughts and ideas via email.

### **Focus Group Processes**

The focus groups were conducted at ACAS, which provides a welcoming and affirming environment for PHAs. The focus groups were conducted by service providers from the target communities, who are familiar with HIV/AIDS related and sexual diversity issues. Informed and written consent was obtained from all participants, with clear explanation that participation was totally voluntary and any withdrawal at any time during the process would not compromise any service provision or any working relationship with ACAS or CAAT. Permission was obtained for facilitators to make notes and audio-tape the focus groups. Agreement was also obtained

among participants to respect confidentiality of personal information within the focus group so as to protect the anonymity and safety of all participants (see Appendix III-A & Appendix III-B).

### **Focus Group Questions**

<b>Focus Group with I&amp;R-PHAs</b>	<b>Focus Group with Service Providers</b>
a. To you, what is mental health?	a. To you, what is mental health?
b. Based on your own experiences or those of your peers, what do you think are the issues faced by immigrant and refugee people living with HIV/AIDS?	b. What are the mental health issues faced by immigrants and refugees PHAs?
c. Based on the mental health issues that you have identified, what types of mental health services do you think immigrant and refugee PHAs need?	c. Based on the mental health issues that you have identified, what types of mental health services do you think immigrant and refugee PHAs need?
d. Based on your own experiences and those of your peers, what can you tell us about the experiences of immigrant and refugee people living with HIV/AIDS in using mental health services in the Greater Toronto Area?	d. Based on your professional experiences, what can you tell us about the experiences of immigrant and refugee PHAs in using mental health services in the Greater Toronto Area?
e. You have identified many important mental health issues and need. If you were going to choose 3 top issues for research in our communities, what would they be?	e. You have identified many important mental health issues and need. If you were going to choose 3 top issues for research in our communities, what would they be?

### ***Key Findings from the Focus Groups***

#### **1. What is mental health?**

A number of PHA participants identified the biological function of the brain, emotional state and the thinking process as key components of mental health; they saw mental health in combination with physical health. One participant articulated that mental health is about the balance of life. He emphasized that it would be hard to separate mental health from emotional health and that mental health also includes spirituality. It includes how one looks at life, self and others.

Another participant made a link between physical wellness and mental health; when PHAs experience reduced functioning and physical illness such as neurological deficit or visual impairment, they also experience increased mental health stress associated with increased dependence on others, decreased self-confidence, negative self-image and social isolation. He shared an experience in which his visual impairment related to the HIV/AIDS disease process

made it difficult for him to walk in the dark, and how someone had mistaken him for “being high” on drugs or alcohol based on the way he walked, thus refusing his entry into a club until he showed his CNIB identity card. He shared that frequent incidents of rejection associated with the visible and invisible disabilities of PHAs could affect their mental and emotional health adversely.

Others identified systemic discrimination and cultural dominance as factors affecting the mental health of I&R-PHAs. Some participants suggested that when people from other cultures or countries do not fit into the ‘norm’, they are thought to be ‘crazy’ by the dominant groups and thus are sometimes mistaken as having mental health problems.

Some participants perceived that stigma towards the term ‘mental health’ is prevalent in their communities; they felt that most people in their community associate the term ‘mental health’ with mental illness; sometimes the term is used as an insult. One participant pointed out that there is a sense of ‘blaming’ in the community, where people with mental illness are thought to have brought it on themselves and to be responsible for it.

Despite the above challenges, many participants recognized that stereotypes and the lack of accurate information contribute to negative connotation of mental health; when people have better understanding about mental health, they will use the hospitals and health services when needed. Moreover, one participant suggested that mental health has something to do with being able to take control of one’s life; it is about the way we deal with life, the way we do things, solved problems and how we interact with one another in the community. To some extent, the participants have given meaning to the WHO definition of mental health: “a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (WHO, 2001).

While the definitions of mental health offered by the PHAs reflected their personal experiences and perceptions, the definitions offered by the service providers reflected their experience at the organizational and systemic levels. Some suggested that mental health as a concept is culturally bound; it is specific to one’s culture, experiences and historical backgrounds. For example, people who had experienced the trauma of war may appear to be not coping well, but knowing what they have gone through, service providers need to learn about their strengths, how they have survived and stayed emotionally healthy. They also need to take into consideration how the clients themselves define mental health.

Others pointed out that mental health is situated in the dimensions of time and space; it is related to one’s social and physical locations, one’s identity, and other factors. It is influenced by

social determinants such as racism, age, housing, sexuality, etc. Racism affects access to health care, income, etc. They reiterated the WHO definition of mental health as a resource for living, as the ability to cope and prosper, however one defines prosperity; but they also pointed out that the WHO definition does not address the historical impact of colonialism on mental health.

The service providers also recognized the impact of access to services on mental health. They associate mental health with how well and how quickly people can adapt to the environment in a new country; how fast one adjusts in terms of language, taking care of one's family and/or children; and getting to know the school or health care system, etc. Thus, they see community connections as an important contributing factor to mental health.

## **2. The mental health needs of I&R-PHAs**

Findings of the focus groups show that the PHA participants and the service provider participants share a similar understanding of the mental health needs of I&R-PHAs even though both groups spoke from different social locations. Moreover, these findings affirm those from the literature search. The key mental health issues and needs of I&R-PHAs are:

- *The Biological-Psychological-Social connection:* Some PHA participants identified that when immigrants or refugee don't speak English, people think there is something wrong with them. One way to acculturate is to learn English, but acquiring a new language or learning new skills for employment could be challenging for many PHAs because the HIV illness affects their cognitive function; some shared that they get tired easily and they have a decreased ability to remember things when compared to the past. Also, some participants found that many people have stereotypes about I&R-PHAs, thinking that they are mentally disturbed or that their illness is contagious. One PHA shared that her memory had deteriorated such that she sometimes could not remember obvious things like her children's birthdays.
- *Social isolation & discrimination:* Separation from loved ones, family or children; loss of pre-migration social support and networks; fear of rejection or discrimination related to disclosure of HIV status or sexuality; lack of opportunity for meaningful participation in employment and in society; and fear of stigmatization within one's social circle and community were identified as factors leading to isolation among I&R-PHAs. In addition, I&R-PHAs have to deal with another layer of stigmatization related to racism. One PHA shared that on top of facing the losses of employment, social status and credentials, refugee PHAs are faced with the loss of dignity when others have the stereotypical images of refugees as being uneducated, poor and taking advantages of the social welfare system. The sense of

'not belonging' affects one's emotion and how one deals with one's HIV status in terms of accessing or adhering to treatment.

- *Stress:* The immigration process was identified as a major source of stress by the refugee PHAs. Some of them indicated that they could not think about their health related to HIV/AIDS when they were struggling to deal with their immigration status and related processes. Refugee hearings can create tremendous stress for them. This finding was echoed by the service providers who shared that uncertainty associated with the immigration process was a key reported source of stress among their refugee clients. Other sources of stress identified are related to basic determinants of health such as housing, income, employment, access to food, financial and social security, and social inclusion. For PHAs living in poverty, housing was a major worry for them. Currently, Fife House has been funded to conduct a research project on the housing needs of PHAs.
- *Depression:* Fear of dying in isolation, fear of stigmatization if HIV status is revealed, fear of becoming ill and having nobody to take care of their children, and negative self-perception after an HIV/AIDS diagnosis were all named as factors that contribute to depression among PHAs. One participant shared that a positive HIV status could affect one's psychological sense of well-being such that one begins to see oneself as 'abnormal'; this changed self-perception is reinforced by the neurophysiological changes and physical illness symptoms experienced by the PHA. Service providers also reported their observation of depression among clients who experienced HIV related illnesses.
- *Mental health issues related to gender:* Both the PHA and service provider participants emphasized that female PHAs are faced with additional stressors related to their gender roles as mothers and caregivers; those who experience violence and economic marginalization are at higher risk of poor mental health. Some service providers reported depression among I&R-PHAs related to the stress of disclosure, particularly among women; they are supposed to disclose to public health information about their sexual partners but at the same time, they are not given the support to do that. There are not sufficient counseling services for PHAs beyond pre- and post-test counseling, particularly in terms of disclosure issues.
- *Mental health issues and needs of non-status PHAs:* One participant pointed out that differences such as the number of years in Canada and whether they have legal status will affect the mental health needs of the different groups of PHAs. Non-status PHAs are faced with increased stress and poorer mental health since their access to any services is limited. Since many non-status PHAs do not have access to health care, they are more likely to be

tested for HIV in a later stage and that affects their overall health status and the management of their HIV/AIDS illnesses.

- *Quality of life:* A number of PHAs raised the issue of quality of life; while acknowledging that being in Canada has enabled I&R-PHAs to access HIV treatment so that they can live longer, their quality of life might not have improved as one participant stated: “Yes, now we live longer, but what for?” Issues that affect their perception about quality of life are related to their struggles for survival and their experiences of social exclusion. A number of them mentioned the effect of stigmatization associated with HIV status on intimacy and relationship; they felt that dating and sexual intimacy have become something beyond their reach.
- *Existential crises:* For many I&R-PHAs, their ‘mental health’ issues are closely linked with their migration and settlement processes. Many came to Canada for a better life, but upon arrival, they are faced with many challenges and barriers in all aspects of their life. Many experience anxiety, depression and a sense of deep loss as they are faced with tremendous uncertainty about their future and their health. Their life seems to be in suspension as they experience a lack of opportunities to connect with society through employment or other meaningful activities; to contribute as full members of society; to develop a sense of belonging; and to fulfill one’s aspiration in life.

### **3. The mental health service needs of I&R-PHAs**

PHA participants identified the needs of services in the following categories:

- Counseling and education that facilitate better coping among PHAs
- Peer support groups in which PHAs have the opportunity to connect with each other
- More services that address gender issues; services that protect women PHAs from the anxiety of having their children taken away by the Children’s AIDS Society when they fall ill; in other words, a built-in support system that allows HIV positive mothers access to adequate support during unpredictable health crises.
- Comprehensive services that address their needs for basic living, settlement and integration, and their HIV/AIDS related health needs.
- Accessible and timely services that meet the language, cultural and other diverse needs of I&R-PHAs related to faith, sexuality, class and socioeconomic status.

Service provider participants identify similar needs as the PHAs; moreover, they express the need for the reorientation of services:

- Client-centered services in which I&R-PHAs are supported in identifying their own health problems and identify appropriate and desirable 'solutions' for their health problems. The service providers acknowledge that people need support but they can develop their own solutions with equitable resources. Moreover, true client-centered care incorporates inputs from PHAs and ensures opportunities for meaningful participation and contribution by PHAs.
- Services that do not pathologize trust. Service providers need to understand the concepts of trust and mistrust in context; they need to understand the roots of mistrust in the clients. Clients are asking: How can I trust that you won't tell people in my community? That you won't stereotype me? That you really care about me? When an organization has staff that reflects the diverse backgrounds in the community, trust will be developed.
- System reform with leadership and commitment to ensure that abuse of power by any service providers in the immigration process, health sector or employment services is prohibited.
- Services that challenge stereotypes and take into consideration the determinants of health disparity and the root causes of the clients' mental health problems.
- Services that offer various models of support beyond medication, including services that address the emotional needs of I&R-PHAs. Participants advocated for more services in counseling, and programs that promote support and social networks; they believe that when PHAs are brought together, a support network will form naturally.
- Service providers also suggested that there is a need for education and professional development for service providers working with I&R-PHAs in terms of increasing their knowledge and understanding about the intersecting issues of migration, HIV/AIDS and mental health. There is also a need for training to promote reflexive practices among service providers and to reduce negative attitude and beliefs towards I&R-PHAs.

#### **4. Experiences of I&R-PHAs in using mental health services**

Focus group participants reported a number of barriers to accessing timely and effective mental health services for I&R-PHAs:

- *Lack of access to culturally and linguistically appropriate services:* A number of PHAs suggested that current health services in the HIV/AIDS sector are still predominantly designed for white, middle-class, gay males such that I&R-PHAs may not feel comfortable accessing the services. One PHA shared that he once joined a program which was developed based on the dominant mainstream culture; throughout the process, instead of feeling helped by the program, he actually became more depressed and he eventually had

to drop out. Others reported that some services that promote emotional health, including counseling and stress reduction classes, are only offered in English; programs that are offered in different languages tend to have long waiting lists and the process of getting services has become a source of stress.

One service provider shared his observation that among the I&R-PHAs that he has worked with, those experiencing language and cultural barriers have comparatively poorer health outcomes. Other service providers suggested that the combined effects of HIV/AIDS related stigma and racism have created barriers to timely treatment; many current services do not necessarily address the specific needs of different communities. Assumptions and stereotypes about a specific community have interfered with how service organizations outreach and provide services to PHAs. In some communities, the lack of timely detection of HIV has led to deterioration of the health of PHAs. For example, it is still difficult to have South Asian women come forward to talk about their illness. Similarly, in the Spanish-speaking communities and the African and Caribbean communities, by the time someone is tested, it may already be too late. Stereotypes about certain communities have prevented effective outreach to the people at risk in those communities. Late detection of the HIV infection means that some PHAs have to cope with the dying of family members and at the same time to deal with their own health problems. As a result, their bereavement is often inadequately addressed. Moreover, many have to deal with immigration issues and other demands, such as their new identity related to HIV, etc.

One service provider reported on a recent case in which a non-status PHA required hospitalization but was refused because staff at one particular hospital insisted that this PHA must have health care coverage. Other participants agreed that the lack of up-to-date information or knowledge about health coverage for marginalized groups, organizational barriers, and abuse of professional power by some service providers all contribute to further suffering among I&R-PHAs, as demonstrated in this case.

- *Lack of services that respect and nurture autonomy and self determination:* Some service providers reported on services that do not encourage I&R-PHAs to partake in their own care plan as autonomous adults.
- *Lack of coordinated services:* Many PHAs and service providers critiqued the current system of HIV/AIDS care for I&R-PHAs in which a PHA has to go through many complicated processes before they are able to access the services. Uncoordinated services mean that I&R-PHAs have to move from one service to another in order to find services that meet their health needs; when that happens, the PHAs have to go through a “retraumatization” process,

as they are required to tell and retell their medical history of HIV infection and other health related problems over and over again. Consequently, available but non-accessible services are not being utilized and therefore become ineffective and inefficient.

- *Systemic and Organizational barriers:* Some services are bound by organizational barriers including rigid time limits assigned to each service category; as a result, clients have to access services at other organizations and in order to receive and go through a system of administrative processes at other organizations in order to receive their needed services. Some of the time restrictions are based on the assumption that clients are homogenous; but in reality, clients require different amounts of time to understand the information or resources being provided, particularly among PHAs with language barriers or experiencing cognitive impairment related to HIV/AIDS.

## **5. Research priorities and questions**

During the focus groups, participants have generated a number of research priorities and questions. Service providers suggested the use of both quantitative and qualitative methodology and research to bring about change. The priority research topics identified were:

1. Assessment of current mental health services for immigrant/refugee PHAs:
  - What types of services exist for immigrant/refugee PHAs? What types of services are PHAs accessing now?
  - What types of services have been effective for immigrant/refugee PHAs who are accessing service? Why are they effective?
  - What needs to be in place for services to become more accessible for immigrant/refugee PHAs who are not accessing these services?
  - How to facilitate a better coordination of these services?
  - Services and care providers: What do they know about the intersection of HIV/AIDS and mental health and migration? How much do they know about HIV/AIDS in relation to mental health and immigration?
2. What is the impact of mandatory testing on the mental health of immigrant/refugee PHAs?
3. How does “time” play in the lives of I&R-PHAs as both immigration and living with HIV/AIDS involve long-term processes? What is the relationship between time and mental health among I&R-PHAs who are newcomers and those who have been in Canada for a period of time. (Doing a longitudinal study- following a group of I&R-PHAs or a cross-section study of different groups of I&R-PHAs - recent immigrant/refugee versus people who have been here for 10 years - with similar circumstances).

Other research topics identified included:

- A more comprehensive study on the mental health issues and needs faced by I&R-PHAs
- Studying HIV/AIDS associated trauma e.g. rape/gang-rape that resulted in HIV/AIDS

- Studying the experience of stigmatization of I&R-PHAs (e.g. stereotypes about drug addicts, etc.)
- Studying the impact of fragmented and inaccessible services on PHA's mental health
- The economic impact of HIV/AIDS (cost) – comparing the “productivity” of people with HIV/AIDS who are accessing services to those who are not.

### **Focus Group Conclusion**

Findings from the focus groups affirm some of the findings identified in the literature search and the program scan. However, existing literature does not address the complex intersecting issues. These findings show that the biological, psychological, social and spiritual dimensions of I&R-PHAs are inseparable. The HIV disease process, stigma, discrimination, and migration/settlement related issues are key stressors to I&R-PHAs. Women PHAs experience additional stressors related to their gender roles and systemic sexism. Uncoordinated and inaccessible services further inflict avoidable stress upon I&R-PHAs. It is clear that there is a need for service reorientation that takes into consideration the complex intersecting factors of HIV/AIDS, citizenship status, gender, sexuality, culture, race, class, age, physical and mental abilities and other dimensions, in the planning, implementation and evaluation of programs and services.

While the focus groups have provided more insight into the mental health issues and needs of I&R-PHAs, there are a number of limitations. Due to the time constraints and limited resources, the PHAs focus group did not include participants who are IDU, transgendered, or homeless. Moreover, all the PHA participants were connected to ASOs and other primary care services; thus, little is known about the needs and experiences of I&R-PHAs who are currently not connected to ASOs. Similarly, the service provider participants were from ASOs, and little is known about the experiences, knowledge and attitude of service providers from the immigration/settlement and mental health service sectors.

The generation of research priorities was invaluable in that they were based on the experiences and ideas of key stakeholders – PHAs and service providers. It became clear that both groups of participants considered action research that would contribute to change and improved access to mental health services for I&R-PHAs as priority.

## **Report Conclusion**

Findings from the literature search and the focus group consultation indicate that mental health is an important issue among people living with HIV/AIDS, particularly among immigrants and refugees. In addition to the stressors faced by PHAs in general, immigrant and refugee PHAs experience additional stressors related to the immigration and settlement process, racism, social exclusion and the lack of access to the determinants of health disparity including poverty, under-housing, social isolation, and barriers to accessing services. Findings from the program scan suggest that it is difficult for I&R-PHAs with language and cultural barriers to access mental health services. While participants identified a number of determinants of mental health for I&R-PHAs, there was a general consensus that there is a lack of comprehensive knowledge on the mental health beliefs and mental health needs of I&R-PHAs; the intersecting effects of HIV/AIDS and migration on mental health; types of mental health services required; how to increase the effectiveness of existing services for the mental health needs of I&R-PHAs; and how to improved access to mental health services for I&R-PHAs.

## Appendix I

### Sexual Orientation (SO) and/or Sexual Partner (SP) Identified

Among 31 articles, only 8 identified sexual orientation and/or sexual partner of research subjects

Group	Total Articles	SO and/or SP not identified	Heterosexual	Same Sex or Bisexual
General	10	9	1	0
MSM	6	0	0	6
IDU	1	0	0	1 MSM
Sex Workers	0	0	0	0
Transgendered	0	0	0	0
Women	8	6	2	0
Youth	6	5	0	1 (MSM)
Total	31	20	3	8

### Highlights

- 65% of articles did not mention sexual orientation and/or sexual partner
- Most researchers assume subjects are heterosexual
- 8 out of 11 articles were MSM (6 MSM, 1 on youth, and 1 in the IDU population)

## Appendix II-A. 211 Directory - Community Health Agencies

Community Agency	Languages of Service identified in 211	Language Interpretation identified in 211	Response	Referred to Other Agency
1. A downtown hospital clinic	Chinese, Italian, Portuguese, Spanish, Vietnamese	√	n/a	
2. A community at York	Somali, Spanish, Vietnamese	none	n/a	
3. A community health agency serving immigrant women	Chinese (Cantonese & Mandarin), Hindi, Italian, Portuguese, Punjabi, Spanish, Tamil, Urdu, Vietnamese	none	n/a	
4. An ethnospecific agency serving family and children	French, Hebrew, Hungarian, Russian, Yiddish	none	n/a	
5. An ethnospecific agency serving family and children	None listed	none	n/a	
6. A neighbourhood service centre	Portuguese, Punjabi, Somali, Spanish, Vietnamese	none	n/a	
7. A local community health centre	Hindi, Italian, Punjabi, Somali, Spanish, Urdu	√	n/a	
8. A community centre serving immigrants	Chinese (Cantonese & Vietnamese), Portuguese, Spanish	none	No Vietnamese language interpretation - referred to two other agencies	A large ASO & a community mental health agency
9. A community health centre serving immigrant & refugee women	Bengali, Hindi, Spanish, Swahili, Twi, Urdu, West Indian dialects, Yoruba	√	Referred to another agency - no reason given	A local community health centre
10. A service agency serving family with specific counseling programs for gay and lesbian individuals.	Bini, Chinese (Cant & Mandarin), Edo, Farsi, Hindi, Hungarian, Italian, Portuguese, Romanian, Serbian, Somali, Spanish, Tamil (Not all languages available for all services)	none	HIV/AIDS related counseling services not offered in other languages at the DK Centre	No referral given

## Appendix II-B. Community Health Service Referrals

2 <sup>nd</sup> Referral	3 <sup>rd</sup> Referral	Response
<p>A local community health centre</p> <p>Response:</p> <ul style="list-style-type: none"> <li>• will meet with team of counsellors to discuss other possible resources</li> <li>• will arrange Vietnamese interpretation for intake</li> <li>• does not do “HIV counseling”</li> <li>• counselling waiting list is 4 months</li> </ul>	<ul style="list-style-type: none"> <li>• An agency working with PHAs</li> </ul>	<ul style="list-style-type: none"> <li>• Waiting for reply</li> </ul>
<p>A large community settlement and community service agency</p> <p>Response: does not provide HIV/AIDS counselling (Website states that it provides supportive counselling in settlement, employment and family)</p> <ul style="list-style-type: none"> <li>• Spoke to Vietnamese counsellor</li> <li>• Does not provide “that kind of counselling”, only helps with form filling, and does do short term counseling</li> <li>• When asked what kind of counseling, he does and could he help my friend he kept insisting on referring me back to intake</li> <li>• He then provided a referral to another ethnospecific counselling agency &amp; stated to “call back if that does not work”</li> </ul>	<ul style="list-style-type: none"> <li>• An Ethnospecific Counselling Agency</li> </ul>	<ul style="list-style-type: none"> <li>• Does not provide Vietnamese language services</li> </ul>

### Appendix II-C. The Chain of Referral to Ethnocultural Community Health & Service Agencies

2 <sup>nd</sup> Referral	3 <sup>rd</sup> Referral	4 <sup>th</sup> Referral	5 <sup>th</sup> Referral	6 <sup>th</sup> Referral	7 <sup>th</sup> Referral	8 <sup>th</sup> Referral
<p>A community mental health agency Response: Does not offer services in Vietnamese</p>	<ul style="list-style-type: none"> <li>• Another community mental health agency* Response: provide service with waiting list</li> <li>• A large settlement and social service agency</li> </ul>	<ul style="list-style-type: none"> <li>• A Chinese counselling service</li> </ul>	<ul style="list-style-type: none"> <li>• A health agency serving immigrant and refugee women **</li> <li>• A Community Care Access Centre Location #1</li> </ul>	<ul style="list-style-type: none"> <li>• Public Health Department</li> <li>• A Community Care Access Centre Location #2</li> </ul>	<ul style="list-style-type: none"> <li>• No follow up</li> <li>• A large ASO</li> </ul>	<ul style="list-style-type: none"> <li>• A small ASO</li> </ul>

<p>*A local mental health agency serving immigrants and refugees</p>	<p>Response: provides mental health service to immigrant PHAs</p> <ul style="list-style-type: none"> <li>• Emailed three weeks ago – no response</li> <li>• Called and was referred to Vietnamese intake worker</li> <li>• Questions asked: does the person have a psychiatric diagnosis? – this would speed up process to see counsellor. Client may have to wait to see counsellor</li> <li>• Waiting to hear back from Vietnamese intake worker</li> </ul>
<p>**A health agency serving immigrant and refugee women</p>	<p>Response: does not provide HIV counselling, - only provides “birth control” counselling</p> <ul style="list-style-type: none"> <li>• Unsure about what agency to refer</li> <li>• Referred to call sexual health at Public Health Department</li> <li>• Asked if they have counseling services – not sure</li> </ul>

**Appendix II- D. Response to Call for Information & Service**

Agency	Expedient and/or rushed	Sensitive	Dismissive
1. An ethno-specific community ASO		√	
2. A mental health agency serving immigrants & refugees #1		√	
3. A local health centre		√	
4. A community health agency serving immigrant and refugee women	√		
5. A large settlement and social service agency			√
6. Large ASO		√	
7. A community mental health agency serving immigrants and refugees #2		√	
8. Community Care Access Service Location #1	√		
9. Community Care Access Service Location #2	√		
10. A family service organization serving Chinese	√		
Total	4	5	1

## Appendix II-E. AIDS Service Organizations

2 <sup>nd</sup> Referral	3 <sup>rd</sup> Referral	4 <sup>th</sup> Referral
<p>A large ASO Response: no Vietnamese Language Service</p>	<ul style="list-style-type: none"> <li>• A small ethnospecific ASO** (see service offered below)</li> <li>• A community health centre serving immigrant and refugee women</li> </ul>	<ul style="list-style-type: none"> <li>• Provides mental health service to immigrant PHAs</li> <li>• Does not provide “HIV counselling”</li> </ul>
<p>A small ethnospecific ASO Response: provides</p> <p>A small community serving PHAs Response: None</p>	<p>**Response from the small ethnospecific ASO: Provides service to immigrant &amp; refugee PHAs</p> <ul style="list-style-type: none"> <li>• Able to provide counselling and assistance for other services</li> <li>• Confirmed letter of HIV status if possible</li> <li>• No identification needed</li> <li>• Can be anonymous</li> <li>• Can provide help with financial service, housing, and other resources</li> <li>• Can also provide support over the phone if necessary</li> <li>• Offered to meet client in a public space</li> </ul> <ul style="list-style-type: none"> <li>• Emailed (three weeks ago) and left phone message – no response</li> </ul>	

**Appendix III-A**  
**Community Focus Group Consent Form**  
**Improving Access to Mental Health Services for Immigrant and**  
**Refugee PHAs – Research Priority**

**Sponsors:**

- Asian Community AIDS Services (ACAS)
- Committee for Accessible AIDS Treatment (CAAT)

With a seed grant from the Ontario HIV Treatment Network (OHTN)

**Purpose of the Community Focus Group:**

- To identify the key mental health issues faced by immigrants & refugees living with HIV/AIDS
- To identify a priority research issue related to mental health service needs of immigrants & refugees living with HIV/AIDS
- The ultimate goal is to improve access to mental health services for immigrants & refugees living with HIV/AIDS

**Consent to participate**

I declare that the purpose of the focus group has been explained to me and any questions that I have about the focus group have been answered. I am aware of my right not to participate and my right to withdraw from the focus group at any time without compromising the service or support I receive from ACAS or CAAT.

I understand that:

- My name or any information that identifies me will be kept confidential.
- The focus group will take about 2 hours
- The focus group will be audio-tape and notes will be taken
- All information collected during the focus group will strictly be used for the purpose of developing research proposals to address treatment access issues faced by immigrants & refugees living with HIV/AIDS

I agree to:

- Respect the confidentiality of other focus group participants

I hereby consent to participate in this focus group conducted by ACAS & CAAT and give permission for ACAS & CAAT to use the information collected as stated above.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Appendix III-B**  
**Service Provider Consent Form**  
**Improving Access to Mental Health Services for Immigrant and**  
**Refugee PHAs – Research Priority**

**Sponsors:**

- Asian Community AIDS Services (ACAS)
- Committee for Accessible AIDS Treatment (CAAT)

With a seed grant from the Ontario HIV Treatment Network (OHTN)

**Purpose of the Community Focus Group:**

- To identify the key mental health issues faced by immigrants & refugees living with HIV/AIDS
- To identify a priority research issue related to mental health service needs of immigrants & refugees living with HIV/AIDS
- The ultimate goal is to improve access to mental health services for immigrants & refugees living with HIV/AIDS

**Consent to participate**

I declare that the purpose of the focus group has been explained to me and any questions that I have about the focus group have been answered. I am aware of my right not to participate and my right to withdraw from the focus group at any time without compromising my working relationship with ACAS or CAAT.

I understand that:

- My name or any information that identifies me will be kept confidential.
- The focus group will take about 2 hours
- The focus group will be audio-tape and notes will be taken
- All information collected during the focus group will strictly be used for the purpose of developing research proposals to address treatment access issues faced by immigrants & refugees living with HIV/AIDS

I agree to:

- Respect the confidentiality of other focus group participants

I hereby consent to participate in this focus group conducted by ACAS & CAAT and give permission for ACAS & CAAT to use the information collected as stated above.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

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